PERCEPTION OF GENETIC RISK IN SEXUAL AND REPRODUCTIVE DECISION-MAKING (PGRID) BY COLLEGE STUDENTS

A Dissertation

by

HEATHER HELAINE HONORÉ

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

August 2008

Major Subject: Health Education

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Approved by:

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August 2008

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ABSTRACT

Perception of Genetic Risk in Sexual and Reproductive

Decision-making (PGRID) by College Students. (August 2008)

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Co-Chairs of Advisory Committee: Dr. Patricia Goodson
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One psychosocial variable, human mate selection, has been studied extensively within the field of evolutionary psychology. A question of interest is how sexual/reproductive decision-making (i.e., dating, marrying, and childbearing) might be influenced by an individual's perception of his/her genetic risk and other psychosocial variables. There is a paucity of empirical studies within the literature exploring this specific relationship.

This partially mixed, sequential mixed methods study addresses how individual perception of genetic risk (PGR) influences or predicts sexual/reproductive intentions and decision-making. A systematic review of the literature was conducted by searching for English language, peer-reviewed, empirical studies in Cambridge Scientific Abstracts databases (N=26). Next, students from three Southwestern universities were recruited for focus groups and responded to 15 open-ended questions (N=86). Transcripts were audiotaped, transcribed verbatim and analyzed using holistic-content analysis. Based on

the literature review and qualitative findings, a 138-item, web-based instrument was designed and tested at two Southwestern universities (N=2,576). Survey data were analyzed using non-parametric univariate analyses and multiple regression.

Approximately 50 demographic, individual/familial psychosocial and genetic testing-related factors influenced the relationship between PGR and sexual/reproductive decision-making in reviewed studies. Individual psychosocial factors (e.g., intention, attitudes) represented 65.8% of all findings. Participants in the qualitative phase exhibited *moderate* health literacy when interpreting and discussing genetic risk information. A number of factors including age, gender, religion, individual/family values, and exposure to genetic concepts/technology appeared to influence sexual/reproductive decision-making.

Demographic, Health Belief Model (HBM) and Theory of Planned Behavior (TPB) variables predicted the relationship between PGR and dating, marital, and childbearing intention in the quantitative phase. TPB variables were the strongest predictors of intention accounting for 33.1-38.7% of variance. Positive family norms were the single best predictor of dating and marital intention. Age was the best predictor of childbearing intention.

Further research is needed to understand how young adults incorporate genetic risk perceptions into sexual/reproductive decision-making. Mixed methods and longitudinal study designs, and structural equation modeling are recommended for use in future studies. Study findings affirm a need for health educators to consider adopting

genomic competencies; creating theory-based curricula/interventions; and forming partnerships with genetic specialists and local/regional health departments.

DEDICATION

Nom myoho renge kyo (Devotion to the Mystic Law of cause and effect through sound)

ACKNOWLEDGEMENTS

> An understanding heart is everything in a teacher, and cannot be esteemed highly enough. One looks back with appreciation to the brilliant teachers, but with gratitude to those who touched our human feeling. The curriculum is so much necessary raw material, but warmth is the vital element for the growing plant and for the soul of the child.—**Carl Jung**

I would like to thank my committee Co-chairs, Drs. Patricia Goodson and B.E. (Buzz) Pruitt, and my committee members, Dr. M. Carolyn Cark, Dr. E. Lisako McKyer, and Dr. Alan Pepper, for their guidance and support throughout the course of this dissertation research study. I thank you for molding me into a researcher, one who is not dedicated to inquiry for love of science, but for love of humanity.

> One who refuses to seek the advice of others will eventually be led to a path of ruin. A mentor helps you to perceive your own weaknesses and confront them with courage. The bond between mentor and protégé enables us to stay true to our chosen path until the very end.—**Daisaku Ikeda**

I would also like to thank my lifelong mentors, Kristin Cotter-Mena, Ph.D., Lisa Whipple, LCSW, Laurie Kidd, LCSW, Shirley Peterson, LCSW, Dale Alexander, Ph.D., Lee-Jane W. Lu, Ph.D., Michael L. Platt, Ph.D., Curt Phifer, Ph.D., Jean D'Amato Thomas, Ph.D., Frasier Snowden, Ph.D., Mrs. Ann Brown, Ms. Sharon Matthews, Mr. John Gerbrecht, Mr. Williams, Ms. Lamotte, Mr. Williams, Donald Russell Bailey, Ph.D., Mr. Timothy Murray, Ms. Patricia Duhon, Mr. Burns, and Mrs. Susan Birdsong.

I am because you were.

> A teacher affects eternity; he can never tell where his influence stops.—**Henry B. Adams**

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> Be courteous to all, but intimate with few, and let those few be well tried before you give them your confidence. True friendship is a plant of slow growth, and must undergo and withstand the shocks of adversity before it is entitled to the appellation.—George Washington

Many thank to my old friends, Christina, P.J., Hank, Thomas, Billy, Lamar, Zanni, Roz, The Marys, Thiago, Cindy, Nancy Jane, Josh, and Peter. *I really do "get by with a little help from my friends."*

> Friendship is born at that moment when one person says to another: What! You too? I thought I was the only one.—**C. S. Lewis**

And, thanks to new friends, Dieula, Joy, Cindy, Sandra, and the 20/30-something BVUUs (Aimee, Mark, Chris, Bruce, Tanya, Jeremy, Meghna, and all). *Love! Laughter! Life!*

> Happiness is having a large, loving, caring, close-knit family in another city.—**George Burns**
>
> Families are like fudge... mostly sweet with a few nuts.—**Anonymous**
>
> Feelings of worth can flourish only in an atmosphere where individual differences are appreciated, mistakes are tolerated, communication is open, and rules are flexible -- the kind of atmosphere that is found in a nurturing family.—**Virginia Satir**

Much love and many thanks for the family ties that bind, but thankfully have not strangled. I love you Mom, Momo, Papa Benny, Aleshia, Sondra (Sam), Jasmine, Cierra, Chris, Kevin, Paul III, Frank, Grandma Shirley, Aunt Marsha (Auntie Diva), Aunt Carmen, Uncle Mark, Uncle Chris, Aunt Gladys, Aunt Jennifer, Aunt Veronica, Uncle Michael, Aunt Sonya, Uncle Isadore, Aunt Marilyn, Uncle Eugene, Aunt Michelle, Christian, Rachel, Jules, Gabby, Dominic, Simone, Martina, Nicole, Mark Jr., Courtland, Patrick, Monique, Aaron, Michael, Shenika, Keisha, Derrek, and all the new little ones.

I would also like to thank my cousin and "brother," Quincy Paul Jones. Knowing you since we were "knee high to a grasshopper" has been one of the greatest joys of my life.

To my partner, Mark, "If you only have one smile in you, give it to the people you Love" (Maya Angelou). Thinking of you always makes me smile.

Last but not least, this dissertation is dedicated to my future, Mariella Rose and Morgan Alexander. We don't know each other yet, but I hope to meet you soon. "Children are the only form of immortality that we can be sure of" (Peter Ustinov).

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CHAPTER I

INTRODUCTION

Almost five years have elapsed since the completion of the Human Genome Project (HGP). Yet scientists, policy makers, and the general public continue to question "*when* and *how* the advances of the [HGP] and other genetic research will be integrated into society, medicine, and public health" (French & Moore, 2003). In the post-HGP era, relevant issues include genetic health literacy, access to genetic services, and the ethical, legal, and social implications (ELSI) of public health genetics and genomics.[1]

A complicating factor lies in the finding that the popular media remains a primary source of genomic information for the general public; however, this "scientific information is often incomplete and/or inaccurate" (Bodzin, Kardia, Goldenberg, Raup, Bach, & Citrin, 2005, p. 1). This results in a public lacking the health literacy necessary for informed decision-making. For example, 2003 National Assessment of Adult Literacy (NAAL) results indicate that only a small number of U.S. adults (12%) were rated as *proficient* in terms of health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006). A higher number of individuals who identified as having *below basic* or *basic* levels of

---

This dissertation follows the style of *Health Education & Behavior*.

[1] While traditional genetics focuses on single-gene effects, genomics focuses on multiple gene and gene-environment interactions (Guttmacher & Collins, 2002). Even though the terms "genetics" and "genomics" refer to differing paradigms, I will be using the terms interchangeably in this dissertation study.

health literacy received their health information from radio or television and not from printed media (Kutner et al., 2006).

The 2003 NAAL also assessed quantitative literacy, or numeracy, in U.S. adults (Kutner et al., 2006). Quantitative literacy involves the increasingly complex range of skills necessary to perform mathematical calculations in everyday life. NAAL quantitative literacy results indicate that, while U.S. adults made gains in this area, subgroups including Black Americans, Hispanics and older adults had the lowest quantitative literacy levels (Kutner et al., 2006).

The concept of genetic risk provides an example of numeracy. This concept is essential to discussions of genetic health and disorders, yet it is one of the most widely misunderstood concepts in science. One reason for confusion is that risk is communicated numerically, yet interpreted subjectively.

A number of demographic and psychosocial variables have been demonstrated to be affected by an individual's genetic risk perceptions. One psychosocial variable in particular, human mate selection, has received extensive treatment within evolutionary psychology and related literature. However, few studies have explored the relationship between individual perception of genetic risk as it influences sexual and reproductive intentions and decision-making, including mate selection.

The Perception of Genetic Risk in Sexual and Reproductive Decision-making (PGRID) by College Students study, reported in this dissertation, attempts to add to the extant body of research by exploring the relationship between genetic risk perception and sexual/reproductive intentions and behaviors. A secondary aim of the overall study

is to test the appropriateness of a mixed methods approach to answering the focal question. According to Johnson and Onwuegbuzie (2004), "research methods should *follow* research questions in a way that offers the best chance to obtain useful answers. Many research questions and combinations of questions are best and most fully answered through mixed research solutions" (pp. 17-18).

Johnson, Onwuegbuzie, and Turner (2007) define mixed methods as "the type of research in which a researcher…combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration" (p. 124). Mixed methods research designs lie along a *continuum* between non-mixed, or *mono-method* (e.g., qualitative or quantitative), and *fully mixed methods* (Leech & Onwuegbuzie, 2007). Designs that fall between these two points are *partially mixed*.

The overall design of this dissertation is that of a *partially mixed*, *sequential* (i.e., the qualitative phase occurs before the quantitative phase) mixed methods research study (see Figure 2 in Chapter III). The study consists of qualitative and quantitative phases, each having equal status (i.e., both paradigms are weighted equally). The first, or qualitative component, consists of focus groups with currently enrolled students, ages 18 and older, at three Southwestern U.S universities. The second, or quantitative component, consists of two phases: an instrument design phase as well as a survey design and implementation phase.

Mixed methods study designs have a distinct advantage in that "most of (the) published mixed methods have been utilized to answer questions that could not be answered by one paradigm alone" (Leech & Onwuegbuzie, 2007). A preliminary review of the literature prior to the dissertation revealed a paucity of empirical studies concerning factors influencing the relationship between perception of genetic risk and sexual/reproductive intentions and decision-making. Thus, another advantage of the overall dissertation design is that corresponding variables and factors emerge from qualitative data collected within the focal area (Strauss & Corbin, 1998).

Emerging variables and factors are then incorporated into the design of a survey instrument. An added advantage is that quantitative data collected using an instrument grounded in qualitative data, may be more effective in capturing the "reality" of the relationship between emerging variables and those variables of interest. Further, quantitative data (e.g., demographics, theory-based factors) may also be used to determine the instrument's psychometric properties, and to refine hypotheses and research questions for future qualitative and quantitative inquiry.

I organized the dissertation into five chapters; chapters II-IV are formatted as journal articles. The first article (Chapter II) presents results from a systematic review of the literature on factors influencing the relationship between perception of genetic risk and mate selection; the second manuscript (Chapter III), reports findings from the study's qualitative phase related to individual perception of genetic risk and reproductive and sexual decision-making; and the third manuscript (Chapter IV) focuses on results

from a survey designed to assess the factors that influence and predict the relationship between genetic risk perceptions and specific sexual/reproductive intentions.

This first chapter (Chapter I) introduces the study and organization of the overall manuscript. Chapter II presents the results from a systematic review of the literature. The purpose of the review was to answer the following questions: a) Which factors (i.e., mediator or moderator variables) influence the relationship between perception of genetic risk and mate selection? and b) What are the methodological characteristics of the research reporting these influences? Using systematic review procedures developed by Garrard (1999), I searched 26 databases within Cambridge Scientific Abstracts using variations and Boolean connectors of the key terms and CSA descriptors related to perception of genetic risk (e.g., perceived risk and genetic, genetic risk perception) and mate selection (e.g., partner choice, mate choice). Twenty-six (N=26) empirical studies were identified using inclusion/exclusion criteria and purling. This systematic review appears to be one of the first conducted using factors influencing genetic risk perceptions and human mate selection; to the best of my knowledge, no reviews have examined the methodological quality of these studies.

Chapter III presents findings from the dissertation study's qualitative phase concerning perception of genetic risk and reproductive and sexual decision-making, including mate selection. The study presented in this chapter had two primary aims: 1) to describe how a sample of young adults conceptualizes abstract ideas such as genetic risk; and 2) to understand how individual perception of genetic risk influences sexual and reproductive decision-making, within this sample. For the purposes of this study, I

created a focus group interview guide consisting of 15 open-ended questions and related probes (see Appendix B). This interview guide was divided into three sections: conceptualization of genetics, conceptualization of genetic risk, and operationalization of genetic risk in sexual and reproductive decision-making. Focus group interviews were transcribed verbatim and analyzed for themes related to the research questions.

Chapter IV presents results from the dissertation study's quantitative phase. The study presented in that chapter aimed at answering the following questions: 1) What psychosocial factors influence genetic risk perceptions and specific sexual/reproductive intentions (i.e., intentions to date, marry, and have children with individuals who are carriers or affected by a genetic disorder)? and 2) Which theory-based variables predict sexual and reproductive intention; specifically, intention to date, marry, and have children with individuals who are carriers or affected by a genetic disorder? For the purposes of this study, I created a web-based survey consisting of 122 open and closed-ended questions. Survey data were collected from currently enrolled students, ages 18 years or older, at two Southwestern U.S. universities. Results were analyzed using non-parametric univariate analyses and multiple regression modeling.

Chapter V summarizes the various "pieces" of the dissertation study and provides a conclusion specifically related to findings from the qualitative and results of quantitative analyses. Chapter V is followed by appendices, which provide documentation related to each of the manuscripts described in this dissertation. Appendices include Appendix A (Alphabetized List of Reviewed Studies), and

Appendix B (Focus Group Interview Guide), and Appendix C (Institutional Review Board documents).

CHAPTER II

PERCEPTION OF GENETIC RISK AND HUMAN MATE SELECTION: A SYSTEMATIC REVIEW

Introduction

The Human Genome Project (HGP), which ended in early 2003, ushered in a period of unprecedented growth in genetics research and technology (National Human Genome Research Institute, 2008). The HGP also spawned a new field of study, *genomics*. While traditional genetics focuses on single-gene effects, this new genetics focuses on multiple gene interactions (Guttmacher & Collins, 2002). Genomic research has growing implications for multi-factorial health conditions such as risk for cardiovascular disease and cancer; however, its role in human health and behavior is evolving.

The concept of risk is essential to any discussion of genetic disorders, yet it is one of the most widely misunderstood concepts in science. According to Hallowell and Richards (1997), genetic risk information may be understood in three ways. The first type of genetic risk is *directly associated* with developing a specific genetic disorder such as Sickle Cell Disease or Huntington's Disease (Hallowell & Richards, 1997). A second type of genetic risk is associated with familial inheritance of disorders such as breast cancer that occur as a result of genetic mutations. Non-genetic risk is the third type of risk. This type of risk would include *age-related risks* including those resulting in children with Down's syndrome (Hallowell & Richards, 1977).

Perception of genetic risk may be defined as an individual's knowledge, attitudes and beliefs concerning the chance that he or she might develop or be a carrier for (i.e., have the genes, but not develop symptoms) a genetic disorder. Risk information may be communicated in *objective* language of *numerical risk*; however, an individual's understanding of this risk (perception of risk or perceived risk) is highly subjective (Hallowell & Richards, p. 38). Inaccurate perceptions of risk may lead to over or underestimation of personal risk that may adversely affect an individual's health behavior (Meiser, Butow, Barratt, Gattasm Gaff, Haan, Gleeson, Dudding, Tucker, & The Psychological Impact Collaborative Group, 2001).

Demographic, psychosocial, and environmental variables may also have an impact on perception of risk (Glanz et al., 2002). One such psychosocial variable with potential impact on perceptions of one's own, and of others' genetic risk, human mate selection, has been studied extensively within the social biology, evolutionary psychology, and biological sciences literatures. Most prominent among theories that address mate selection, Evolutionary Psychology (EP) theory has extensively (and Evolution Theory, less extensively) explored the relationship between genetic risk and sexual and reproductive health decisions, via mate selection cues and strategies.

Evolutionary psychologists hypothesize that human males prefer cues that signal good physical (and possibly genetic) health (Allegeier & Wiederman, 1994; Buss, 2000; Geary, Vigil, & Byrd-Green, 2004). Characteristics associated with health and fertility include "smooth skin, good muscle tone, lustrous hair, full lips"; younger females, thus, rate higher on such measures of attractiveness than older females (Allegeier &

Wiederman, 1994, p. 232). Conversely, females are predicted to favor older males with better social and economic resources.

Based on EP theory, males and females also differ in terms of mate selection strategies. These differences may be due to differential requirements in *reproductive potential* and *parental investment* (Allegeier & Wiederman, 1994; Geary et al., 2004; Simpson & Gangestad, 1992; Sterelny & Fitness, 2003; Woodward & Richards, 2004). EP predicts that women use criteria that are more stringent for partner selection and opt for long-term relationships due to higher parental investment costs. In contrast, men are predicted to favor short-term relationships, as the potential investment costs are low in comparison to reproductive potential (Allegeier & Wiederman, 1994; Geary et al., 2004; Woodward & Richards, 2004).

Mate selection cues and strategies favor specific evolved physical and psychosocial characteristics, but apparent physical health (phenotype) sometimes belies an internal disease state (genotype). Individuals who are genetic disorder carriers often appear *healthy*, yet may have traits that will develop into full-blown disorders later in life (e.g., breast cancer and Huntington's disease) or manifest in their children (e.g., Sickle Cell Disease and Cystic Fibrosis). Conversely, asymmetric facial features, abnormal head size (e.g., microcephaly and macrocephaly), or webbed-fingers and toes are often associated with genetic mutations or disorders. Given the evolutionary pressures to produce healthy offspring, risk perceptions and interpretations may factor into the mate selection process.

One question of interest is how an individual's or a potential mate's genetic risk contributes to his or her mate selection strategies. This systematic literature review adds to a small, but growing body of research by consolidating and evaluating studies on the nature of the relationship between perception of genetic risk and human mate selection. The review specifically answers the following questions: a) Which factors (i.e., mediator or moderator variables) influence the relationship between perception of genetic risk and mate selection? and b) What are the methodological characteristics of the research reporting these influences?

Method

This systematic literature review was conducted using Garrard (1999)'s Matrix Method. The method provided "both a structure and a process for systematically reviewing the literature" (Garrard, p. 17). After the literature search, we abstracted all of the salient information contained in the reviewed studies into a modified version of Garrard's Review Matrix. We then synthesized the information and used it as the foundation for the systematic literature review itself.

Cambridge Scientific Abstracts (CSA) is publication 'warehouse' providing electronic access to 100 databases and journals subdivided by content area (CSA, 2008). Given the multi-disciplinary nature of this systematic review, we decided to use databases related to the *natural* and *social sciences*, as well as *technology* (CSA, 2008). Twenty-six CSA databases were searched in April 2006 and again in April 2008. These databases included *AIDS and Cancer Research Abstracts*, *Biological Sciences, Biology*

Digest, BioOne Abstracts and Indexes, Biotechnology and Bioengineering Abstracts, Communication Studies, Conference Papers Index, EconLit, Education, ERIC, Health Sciences, MEDLINE, PAIS International, Physical Education Index, Political Science, PsycARTICLES, PsycBOOKS, Psychology, PsycINFO, Safety Science and Risk, Social Services Abstracts, Sociological Abstracts, Sociology, TOXLINE, Urban Studies & Planning, and *Worldwide Political Science Abstracts*.

Literature searches employed variations and Boolean connectors of the key terms and CSA descriptors *attitude to health*, *carrier state: psychology, choice behavior, consanguinity, dating, decision-making*, *genetics, genetic counseling, genetic diseases inborn: prevention and control; genetic predisposition to disease: psychology, genetic risk, genetic screening: psychology, human courtship, human mate selection, interpersonal relations, life-history, mate choice, marriage, medical decision-making, perceived risk, predictive testing, pregnancy, prenatal diagnosis: adverse effects, psychosexual behavior, reproductive behavior, sexual behavior*, (*marital, dating, family, romantic*, and *sexual*) *relationships, sexual intercourse: human*, *social dating,* and *spouses: psychology*. References of reviewed studies were also examined, or purled, for additional studies of interest. Purling has been used in numerous systematic literature reviews and allows the reviewer to add studies to his or her sample that might have been missed during electronic database searches. [Examples of purling within recent scientific articles include Honest, Sharma and Khan (2006), Herrington and Fowler (2006), and Peng, Ye, Tan, and Zhou (2006).] When qualifying studies that were missed

during electronic searches are included, their addition has the net effect of increasing the final sample size.

Inclusion and Exclusion Criteria

A broad approach was used for key term searches and inclusion and exclusion criteria. Articles considered for inclusion in this review had to: a) be published in peer-reviewed journals; b) be written in English language or translated into English; and c) employ empirical methods to examine the relationship between perception of genetic risk and human mate selection.

Initially, no restrictions were placed on publication year; however, articles selected using the purling technique were only included if they were published between 1996 and the present. This limitation was imposed in an attempt to decrease the effects that advances in genetic testing, exposure to media, and other historical developments might have on perception of genetic risk. For example, the Huntington disease mutation was identified in the early 1990's, but genetic testing for hereditary breast cancers (BRCA 1 and BRCA 2) was not widely available until the late 1990's [4, 10].

Studies were excluded from the review if they: a) were literature reviews, theoretical pieces, comments, reports, opinion papers, or letters to the editor; b) focused only on perception of genetic risk, and did not explicitly report a relationship between perception of genetic risk and human mate selection; and c) were case reports with a sample size of one. Twenty-six studies met the inclusion and exclusion criteria for

inclusion in this review (See Appendix A). Most of these studies were indexed in MEDLINE and PsycINFO.

Methodological Quality Assessment

Criteria were established to assess the conceptual and methodological quality of the reviewed studies. These criteria provided a rating system for studies' theoretical orientation, operationalization of variables, research paradigm, sample size and design, participant characteristics, ethics, and data analysis. Each study was evaluated and received points for individual criteria and a total methodological quality score (MQS; Goodson, Buhi, & Dunsmore, 2006a). If a study contained multiple elements for the same criterion, the higher point value was awarded. In order to provide some measure of equity, an attempt was made to ensure that qualitative or mixed methods studies were not rated more severely than quantitative studies in certain categories. For example, qualitative analysis received 2 points, or the equivalent of points awarded for bivariate analysis, rather than 1 point for univariate/descriptive analysis.

MQSs for this review ranged from 7 to 15 points (minimum possible score=4 points and maximum possible score=20 points). Table 1 contains the MQS criteria and frequency distribution for each criterion. Table 2 presents a summary of individual criterion and total scores for each reviewed study, as well as descriptive statistics for the final sample (N=26).

Table 1. MQS Criteria for Reviewed Studies (N=26)

Criteria	Score	Frequency (n)	%
C1: Operationalization of the DV			
Did not provide operational definition of IV and DV (References #)	0	**19**	73.1
Provided operational definition of IV and DV (References #)	1	**7**	26.9
C2: Theory			
Did not use theory	0	**1**	3.8
Implicit, theory-based explanation for relationship between the IV and DV	1	**17**	65.4
Explicit, theory-based explanation for relationship between the IV and DV	2	**8**	30.8
C3: Instrumentation			
Did not use instruments (survey, questionnaire, etc.)	0	**3**	11.5
Used instruments, included description but reliability/validity not discussed	1	**19**	73.1
Used instruments, included description and reliability/validity was discussed	2	**4**	15.4
C4: Study Design			
Qualitative	1	**13**	50
Quantitative	1	**8**	30.8
Mixed Methods	2	**5**	19.2
C5: Sampling			
Non-random or convenience sample	1	**18**	69.2
Non-random/convenience sample + comparison group	2	**6**	23.1
Random sample	2	**2**	7.7
C6: Sample Size			
n<30 = Small	0	**7**	26.9
30=< n < 300 = Medium	1	**13**	50
n>=300 = Large	2	**6**	23.1

Criteria	Score	Frequency (n)	%
C7: Research Ethics			
Informed consent procedures not explained, little or no evidence of discussion concerning confidentiality or potential risks/benefits of genetic testing	0	**12**	46.2
Informed consent procedures explained, evidence of discussion concerning confidentiality or potential risks/benefits of genetic testing	1	**14**	53.8
C8: Demographics: Gender			
Female-only sample	0	**3**	11.6
Sample contained both genders, females were any age	1	**16**	61.5
Sample contained both genders, females were <35 years	2	**7**	26.9
C9: Demographics: Familial History			
Sample only included individuals with a family history of a genetic disorder	0	**11**	42.3
Sample included individuals with and without a family history of a genetic disorder	1	**15**	57.7
C10: Demographics: Race/Ethnicity			
Sample contained one racial/ethnic group, or race not described for sample	0	**22**	84.6
Multi-Racial/ethnic sample	1	**4**	15.4
C11: Data Analysis			
Univariate Statistics / Descriptive (frequencies and mean distributions; percentages)	1	**3**	11.6
Qualitative (content analysis; emergent themes analysis; grounded theory; etc.)	2	**14**	53.8
Bivariate Statistics - Correlation or Crosstabulation (Chi-Square)	2	**5**	19.2
Multiple/Logistic Regression	3	**1**	3.8
Multivariate Statistics – Canonical correlation analysis; discriminant function analysis; path analysis, structural equation modeling	4	**3**	11.6
	20	**N=26**	**100%**

Table 2. Summary of MQS Review Criteria Scores (minimum score=4 points, maximum=20 points)

Citation		C1	C2	C3	C4	C5	C6	C7	C8	C9	C10	C11	MQS Total Score
Qualitative Studies													
1. Abeliovich et al. (1996).	Ql	0	1	0	1	2	2	1	2	1	0	1	**11**
3. Bombard et al. (2008).	Ql	1	1	1	1	2	2	1	1	0	0	2	**12**
4. Bou-Assy. (2005).	Ql	0	2	1	1	1	1	0	1	1	0	2	**10**
5. Brouwer-Dudokdewit et al. (2005).	Ql	1	1	1	1	1	0	0	1	1	0	2	**9**
7. Geller et al. (1996).	Ql	1	0	1	1	1	3	1	1	1	0	2	**12**
10. Holt (2006).	Ql	1	2	1	1	1	1	0	1	0	0	2	**10**
11. Kay & Kingston (2002).	Ql	0	2	1	1	1	0	1	0	0	0	2	**8**
15. McConkie-Rosell et al. (1999).	Ql	0	1	2	1	0	1	0	1	0	0	2	**8**
19. Raz & Atar. (2004a).	Ql	0	1	1	1	1	1	0	2	1	0	2	**10**
20. Raz & Atar (2004b).	Ql	0	1	1	1	1	1	1	2	0	0	2	**10**
23. Sobel & Cowan (2000).	Ql	0	2	1	1	1	1	1	1	0	0	2	**10**
24. Taswell & Shotes. (1999).	Ql	0	1	0	1	1	0	1	1	1	0	2	**8**
26. Werner-Lin (2007).	Ql	1	2	1	1	1	1	0	0	1	0	2	**10**
												Mean	**9.8**
Quantitative Studies													
2. Ahmed et al. (2002).	Qn	0	1	1	1	2	2	1	1	0	0	1	**10**
6. Cappelli et al. (2001).	Qn	0	2	1	1	2	1	1	1	1	1	4	**15**
9. Holloway et al. (1994).	Qn	0	1	1	1	1	1	1	1	0	0	2	**9**
12. Keskin et al. (2000).	Qn	0	1	1	1	1	2	0	2	1	0	1	**10**
13. Kornreich et al. (2004).	Qn	0	1	0	1	2	2	1	1	1	0	2	**11**
17. O'Connor & Cappelli (1999).	Qn	1	2	2	1	1	1	0	1	1	1	4	**15**
18. Raz & Atar. (2005).	Qn	0	1	1	1	2	1	1	2	1	0	2	**12**
25. Tibben et al. (1997).	Qn	0	2	2	1	2	1	1	1	1	0	4	**15**
												Mean	**12.1**
Mixed Methods Studies													
8. Hern et al. (2006).	MM	0	2	2	2	1	0	1	2	0	1	2	**13**
14. Lewando-Hundt et al. (2001).	MM	1	1	1	2	1	2	0	1	0	0	2	**11**
16. McConkie-Rossel et al. (1997).	MM	0	1	1	2	1	0	0	0	0	0	2	**7**
21. Raz (2003).	MM	0	1	1	2	1	1	0	2	1	0	2	**11**
22. Shiloh et al. (1995).	MM	0	1	1	2	2	1	0	1	1	1	3	**13**
												Mean	**11.0**
		C1	**C2**	**C3**	**C4**	**C5**	**C6**	**C7**	**C8**	**C9**	**C10**	**C11**	
	Qual=Ql Quan=Qn Mixed=MM											**Mean=10.8 points** **SD=2.2** **Median=Mode=10** **Skewness=0.50**	

Human Mate Selection and Findings

This study reviewed factors influencing the relationship between perception of genetic risk (i.e., the independent variable, IV) and human mate selection (i.e., the dependent variable, DV). None of the reviewed studies explicitly defined mate selection. For the purpose of this review, human mate selection was defined as the process and factors related to an individual seeking out another individual for the express purpose of dating, romantic, sexual, long-term, or marital relationship. This definition includes mate selection that might intentionally, or unintentionally, lead to reproduction.

Types of factors (i.e., moderator or mediator variables) influencing the relationship between perception of genetic risk and mate selection included demographic, individual psychosocial, familial psychosocial, and genetic testing-related variables. For example, the demographic variable, age, was negatively associated with intention to undergo carrier testing, thus definitively determining genetic risk [11]. Older adults were less likely to desire carrier testing as they were more likely to be married and have children (i.e., a negative association). When a reviewed study contained an association between a factor and the variables of interest, this finding was assessed for evidence of a directional relationship between the factors and variables of interest. When available, the direction of this relationship was recorded in Table 3. Each reviewed study could contribute multiple findings; these finding might vary in terms of directionality of association between factors and the IV-DV set.

Table 3. Summary of Factors within Reviewed Studies (N=26 Studies; 193 findings)

	Nature of Finding/Relationship			
Factors associated with perception of genetic risk and mate selection	**Positive Association (Study #)**	**Negative Association**	**Undefined or Bi-directional Association (Study #)**	**Total (# findings)**
Demographics				
Age		4, 16, 26		3
Gender			18-20 (male), 18-21 (female)	7
Religion			4, 14, 18, 21	4
Consanguineous marriage		4	14, 18, 19, 21, 22	6
Subtotal		**4**	**16**	**20**
Individual Psychosocial (Knowledge, Attitudes, Beliefs)				
Inaccurate Knowledge of Genetic Disorder (in general)			4, 11, 24	3
Inaccurate Knowledge of Genetic Disorder (inheritance beliefs based on "folk" wisdom/tradition)		4, 23	11, 18, 19, 24, 26	7
Knowledge of Carrier Status	2, 16, 26	22, 23	1, 11-13, 19	10
Negative Attitude towards Genetic Disorder	15, 16, 26			3
Views on abortion, independent of religious beliefs	12, 21		11, 14, 19	5
Carrier choices in helping professions			8	1
Choice of college location			8	1
Use of Contraceptives (by carrier)	11			1
Orientation towards personal responsibility for reproductive choices	11			1

Table 3. Continued

	Nature of Finding/Relationship			
Factors associated with perception of genetic risk and mate selection	**Positive Association (Study #)**	**Negative Association**	**Undefined or Bi-directional Association (Study #)**	**Total (# findings)**
Individual Psychosocial (Knowledge, Attitudes, Beliefs)				
New awareness as result of test	16, 23			2
Perception of genetic risk (own or future partner)	9-12, 18, 20, 22-24	26	4, 5, 7, 14, 16, 19	16
Perceived benefit of genetic testing			6, 10	2
Ability to minimize perceived risk (i.e., denial)		5, 11		2
Ability to cope with + carrier test result		5		1
Worry about future children	5, 11, 15, 25			4
Feelings of guilt, anxiety, etc. that have/would result from "passing on" disorder	5, 11, 25			3
Worry about being rejected by current or potential partner	3, 20, 26	8, 10, 14, 23, 24	25	9
Intention to have children	10, 26	8, 9, 15, 16, 22, 24	4, 5, 7, 11, 12, 18, 19, 25	16
Intention to have additional children (when already has at least 1 healthy child)		2, 21		2
Intention to have safe sex (to prevent unplanned pregnancy)	8			1
Intention to become sexually active		15 (parental view), 26		2
Intention to choose mate or get married	10	16, 20, 24,	4, 5, 7, 8, 11, 12, 14-16, 18, 19, 26	16
Intention to choose mate or marry someone with a similar disorder or disability	7			1
Intention towards current mate, partner, relationship			9	1

Table 3. Continued

Factors associated with perception of genetic risk and mate selection	Nature of Finding/Relationship			
	Positive Association (Study #)	**Negative Association (Study #)**	**Undefined or Bi-directional Association (Study #)**	**Total (# findings)**
Individual Psychosocial (Knowledge, Attitudes, Beliefs)				
Intention to do predictive/carrier testing before mate selection or marriage	8			1
Decision to have a baby (even with + carrier status)	10	26	5	3
Intention to undergo voluntary sterilization	11, 26	5	9	4
Perceived severity of reproductive outcomes	21, 22, 24		15	4
Subtotal	**45**	**28**	**54**	**127**
Test-related Factors				
Screening program is culturally sensitive			2, 18, 22	3
Cost of genetic testing			4	1
Perception of accuracy of test		4, 5, 18, 19		4
Perception of efficacy of tests in preventing genetic disorders		4, 14, 18-20		5
Testing created "false sense of security" (initial believes they're free of genetic disorder)		4		1
Knowledge concerning the limitations of genetic testing		14	22	2
Worry about Confidentiality, disclosure of results		19, 20		2
Worry about stigmatization		3, 20, 23, 24		4
Subtotal		**17**	**5**	**22**

Table 3. Continued

	Nature of Finding/Relationship			
Factors associated with perception of genetic risk and mate selection	**Positive Association (Study #)**	**Negative Association (Study #)**	**Undefined or Bi-directional Association (Study #)**	**Total (# findings)**
Family and Experiential History				
Family History of Genetic Disorder, 1st or 2nd degree relative	9-11, 19, 20, 22, 24-26		4, 5	11
Level of exposure to individual with genetic disorder	11-Sep			3
Level of family support/approval	20	4, 23, 26		4
Cautioning about risk (from parents) during development	8, 10			2
Social Support/approval	2, 11	4, 18		4
Subtotal	**17**	**5**	**2**	**24**
			Total findings	**193**

Results

The initial search conducted in April 2006 yielded more than 5,800 articles containing some combination of the search terms (this figure includes articles that were counted multiple times due to overlap in search terms.) Most of these articles were not included in this review because they failed to meet our inclusion criteria (e.g., they were non-peer reviewed and non-empirical) or they focused only on perception of genetic risk, and not on the relationship between this risk perception and mate selection. Fourteen articles met the inclusion and exclusion criteria [2, 4-6, 8, 9, 11, 12, 15, 18-22]. Their reference lists were then examined (or purled) for additional articles of interest yielding eight additional studies [1, 13, 14, 16, 17, 23-25]. An April 2008 search for the time period between April 2006 and April 2008 yielded only three additional studies [3, 10, 26]. Purling these articles' reference lists yielded one additional study [7].

Studies' Characteristics

Of the 26 reviewed studies published between 1994 and 2008, most (n=17; 65.4%) were published in the year 2000 or later (See Appendix A). Nineteen journals, representing multiple disciplines, published articles on the relationship between perception of genetic risk and human mate selection. Six journals, *The American Journal of Medical Genetics* [15, 16, 23], *The European Journal of Human Genetics* [1, 3], *Family Process* [5, 26], *Marriage & Family Review* [4, 18], *Psychology, Health & Medicine* [6, 17], and *Social Science & Medicine* [12, 20], published one half (50%) of

the reviewed studies. Almost one third (30.8%) of the studies were published in medical and applied genetics journals [1, 3, 9, 10, 13, 15, 16, 23].

The *Health Belief Model* was a dominant theoretical paradigm in this literature; this finding was reflected in the implicit and explicit theories in the reviewed studies [6, 12, 17]. Other theories included the *Family Life Cycle* [5], *Family Systems Theory* [23], *Interpretive Phenomenological Analysis* [10, 11], *Grounded Theory* [3], the *Resiliency Model of Family Stress, Adjustment, and Adaptation* [8], *Social Representation* [4], and *Stress Response Theory* [25].

Studies' Methodological Quality

Each reviewed study (N=26) received a methodological quality score (MQS) based on criteria adapted from Goodson et al. (2006a) and Locke, Silverman and Spirduso (1998). Table 1 presents the frequency distributions for each MQS criterion. MQS scores ranged from 7 to 15 points (minimum possible score=4 points and maximum possible score =20 points). The mean total MQS for reviewed studies was 10.8 points (SD=2.2). The mode and median for MQS scores were identical (Mode=Median=10 points). These statistics were close to the mean, but the overall distribution of scores was slightly positively skewed (e.g., the mean was greater than the median; Skewness=0.50). More studies (n=14) scored below the mean total MQS score than above.

Reviewed studies employed a variety of research paradigms, operational definitions for variables of interest, and varied in their application of theory. While most

studies were either qualitative (50%) or quantitative (30.8%), mixed methods studies were well represented [8, 14, 16, 21, 22]. Regarding operationalization of variables the majority of studies failed to define the independent (IV) and dependent (DV) variables (73.1%). Most investigators also failed to explicitly use theory for explaining the relationship between the IV and DV (e.g., explicit use of theory was only 34.6%). Failure to clearly define variables and to apply theory may also have had an impact on the types and quality of instruments used to measure the IV and DV. Less than one-fifth (15.4%) of reviewed studies used previously-tested instruments.

Studies also varied in terms of sample size and sampling technique. Most (50%) used medium-size (e.g., $30< n< 300$) and non-random or convenience samples (69.2%). Only two studies (7.7%) used random sampling techniques [1, 18]. Randomly selected samples were either medium-size ($30\leq n<300$) [1] or large (e.g., $n\geq 300$) [18].

Reviewed studies varied considerably regarding sample demographics. Samples from 23 studies contained both males and females; however, seven reviewed studies explicitly used mixed gender samples with females under age 35 years (i.e., females not of advanced maternal age) [1, 8, 12, 18-21]. Three studies [11, 16, 26] used female-only samples, and no studies over-sampled for males or used male-only samples. Fifteen reviewed studies (57.7%) also used mixed family genotype samples (i.e., individuals with a family history of genetic disorders as well as those without a family history). Most studies (n=16; 84.6%) used a homogenous racial or ethnic sample, or did not describe study participants' race/ethnicity (n=6). When race or ethnicity was noted, the most commonly studied racial or ethnic populations were Ashkenazi Jews [1, 13, 22],

Bedouins [14, 18-21], or Caucasians (including Canadians and Europeans) [5, 6, 8, 11, 16, 24-26].

Reviewed studies also received MQS points based on their data analysis technique. Studies utilizing multiple analytic techniques were awarded points based on techniques yielding the highest point values. For example, more than one half (53.8%) of reviewed studies performed a type of qualitative data analysis (e.g., were awarded 2 points). However, three mixed methods studies also used bivariate [8, 16] or multiple/logistic regression [22] analyses. These studies received three points instead of two. Quantitative design studies used a variety of techniques; several used bivariate [9, 13, 15] or multivariate [6, 17, 25] statistical analyses. Only two quantitative studies utilized univariate and descriptive statistics as their highest level of analysis. These studies primarily focused on reporting epidemiological data [1, 2].

Additionally, reviewed studies were assessed for evidence of informed consent. Genetic health risk or status is generally considered sensitive information. Empirical studies that confirmed Institutional Review Board approval of study methods and procedures, as well as related assessments of participant risks, benefits, and protections, were considered to have provided evidence of meeting basic U.S. human research study regulations. A detailed description of this process had to include information concerning how confidentiality would be maintained and potential risks and benefits of genetic testing. Studies that explicitly described how they complied with human research study regulations were viewed as increasing transparency of their research studies and were rewarded one MQS point accordingly. Reviewed studies (53.8%) awarded this MQS

point varied in terms of the depth and breadth of their description of consent and displayed minimal evidence of discussion concerning confidentiality, potential risks, and benefits [1-3, 6-9, 11, 13, 18, 20, 23-25]. Studies with little or no discussion of these elements received zero MQS points.

While reviewed studies did not receive MQS points based on investigation of specific genetic disorders, frequencies of these genetic disorders were recorded for future analysis. A number of studies (42.3%) focused on perception of risk for inheriting autosomal recessive disorders, specifically thalassemia, sickle-cell anemia, cystic fibrosis, phenylketonuria, hematochromatosis, and mucopolysaccharidosis [1, 2, 4, 7, 13, 14, 17-21]. Of this number, several reviewed studies focused on thalassemia or sickle cell anemia resulting from consanguineous marriages [2, 4, 14, 18-21]. Only one autosomal dominant disorder, Huntington's disease, was represented; however, this disorder was the focus of 23.1% of all reviewed studies [3, 5, 7, 10, 24, 25]. Studies focusing on breast or ovarian cancer resulting from BRCA 1 and BRCA 2 mutations [6, 26], as well as X-chromosome-linked disorders including Fragile X and Duchenne muscular dystrophy [11, 15, 16], and Hemophilia [8], were also included in this systematic review.

Studies' Empirical Findings

A number of reviewed studies (n=16) contained information concerning an explicit relationship between perceived genetic risk (of the individual or his or her future mate's) and mate selection [5, 7, 9-12, 14, 16, 18-20, 22-24, 26]. The largest group of

findings revealed a positive association (n=9 findings) between the variables of interest [9-12, 18, 20, 22-24]. Specifically, higher estimates of an individual's (or a potential mate's) risk for developing or "passing on" a genetic disorder led to more conservative mate selection behavior.

Only one study contained a negative association between the variables [26]. In this study, a participant reported that positive BRCA mutation status, and higher perceived risk for developing breast cancer, led to changes in her "life plans," including "finding a partner" (pp. 345-346). The participant was "desperate" to find a partner for a "loving, committed relationship" and having children (pp. 345-346). In this case, higher perceived genetic risk was associated with less conservative mate selection behavior.

The remaining studies exploring this relationship reached bi-directional or inconclusive findings (n=6) [4, 5, 7, 14, 16, 19]. This type of association was noted each time a study revealed results or participant self-reports that were inconclusive or contradictory (i.e., contained both positive and negative associations). Specifically, participants in these studies were often divided in terms of whether or not genetic risk perceptions would influence partner selection. For example, Bedouin participants in two premarital screening studies reported that higher genetic risk does not influence their selection of marital partners. Yet, these same studies contained participants who refused arranged marriages due to their or their partner's positive carrier status and thus higher risk for having affected children [4, 19].

Table 3 presents the various factors found to influence the relationship between perception of genetic risk and human mate selection as reported in the 26 reviewed

studies. There were 193 total findings, or an average of 7.7 findings per study (range 1-13). Individual psychosocial predictors (n=127) represented 65.8% of all findings.

Individual Psychosocial Factors

Individual psychosocial factors included knowledge, perceptions, attitudes, intentions, and affect. Intentions represented the largest group within these types of factors (n=49 findings; 38.9%). The most common findings were related to intention to have children [4, 5, 7-11, 12, 15, 16, 18, 19, 22, 24, 25], intention to choose a mate/marry [4, 5, 7, 8, 10-12, 14-16, 18-20, 24, 26], and the variables of interest (e.g., perception of genetic risk and mate selection). A negative/inverse association occurred when individuals with higher risk perceptions proceeded with partner selection, but had low childbearing intentions [8, 9, 15, 16, 22, 24]. A number of these individuals opted out of having children. Conversely, some individuals with higher risk perceptions proceeded with partner selection and had high childbearing intentions [10, 26]. Several reviewed studies contained such bi-directional or inconclusive (mixed) associations (i.e., the totality of a study's findings contained both positive and negative associations) [4, 5, 7, 11, 12, 18, 19, 25].

Findings related to inaccurate knowledge concerning a specific genetic disorder [4, 11, 24] or one's carrier status [1, 2, 11-13, 16, 19, 22, 23, 26], and inaccurate knowledge due to folk or family tradition were the second largest group of individual psychosocial findings (n=20; 15.9%). Positive associations included instances where increased knowledge of one's (or a partner's) carrier status influenced genetic risk

perceptions leading to more conservative mate selection (n=3 findings) [2, 16, 26]. No other types of knowledge factors were positively associated with the IV-DV set. Rather, the majority of findings in this area contained negative or bi-directional associations. Lower levels of knowledge of carrier status, for instance, were associated with higher perceived levels of genetic risk and more conservative attitudes towards mate selection [22, 23].

Findings concerning affective (n=16; 12.6%) and attitudinal (n=19; 15%) factors also exerted an influence on the relationship between the IV and DV. Affective factors included feelings or emotional responses to perceived genetic risk and the resulting impact on mate selection. Findings in this area were related to worry about being rejected by a partner [3, 8, 10, 14, 20, 23-26], worry about future children [5, 11, 15, 25], and negative feelings concerning "passing on" a genetic disorder [5, 11, 25]. A higher number of affective findings were positively associated with the variables of interest. Specifically, increased affect was associated with higher risk perceptions and more conservative mate selection.

Attitudinal factors included values and beliefs related to various topics/objects, such as views on abortion [11, 12, 14, 19, 21] and contraception [11], or ability to cope with genetic test results [5]. Overall, these factors were positively associated with the variables of interest. For example, an increasingly negative attitude towards inheriting a genetic disorder was associated with higher perceived risk and mate selection [15, 16, 26]. Fewer reviewed studies contained negative [5, 11] or bi-directional/mixed [8, 11, 14, 19] associations.

Perceived severity of reproductive outcomes (n=4 findings) and perceived benefits of genetic testing (n=2) were the final individual psychosocial factors influencing genetic risk perceptions and mate selection. Two studies [6, 10] contained findings related to the perceived benefits factor. These findings contained bi-directional/mixed associations, implying that study participants differed in terms of whether this benefit would or would not alter the relationship between perceived risk and mate selection. In contrast, findings related to the perceived severity factor were positively associated with the variables of interest. Increasing perceptions concerning the severity of reproductive outcomes increased study participants' perceived genetic risk, thus leading to more conservative mate selection, with one exception. A study examining parental views on childhood genetic testing reported that parents' level of perceived severity influenced their risk perceptions of potential reproductive outcomes, and their impressions of how their *children* might approach mate selection [15]. This study provided a bi-directional finding as parents' higher perceived severity and risk led them to encourage more conservative sexual and mate selection practices; however, it was unclear whether their children complied with this practice.

Family Psychosocial Factors

Family and related experiential factors accounted for 12.4% of total findings in this review (n=24). Most (75%) of these factors were positively associated with perception of genetic risk and mate selection. For example, individuals with a family history of a genetic disorder in a first or second-degree relative often perceived

themselves to have higher levels of genetic risk and were overall more conservative in their decision-making. Similarly, increased exposure to a relative affected by a genetic disorder often resulted in higher perceptions of genetic risk and, ultimately, more conservative mate selection. Other family and experiential factors included level of family support [4, 20, 23, 26], social support (in general) [2, 4, 11, 18], and cautions about familial risk for inheriting disorders during childhood [8, 10].

Demographic Factors

Demographic factors such as age [4, 16, 26], gender [18-21], religion [4, 14, 18, 21], and consanguineous marriage [4, 14, 18, 19, 21, 22] accounted for 10.4% of all findings in this review. More demographic findings had a bi-directional/mixed (45%) or negative (40%) association with the variables of interest than positive (15%). Religion was one example. Some individuals who expressed religious views were opposed to assessing one's genetic risk using predictive testing, as a precursor to mate selection, while others believed that their religious beliefs were compatible with the practice [4].

No findings were identified for demographic variables such as race, educational attainment, and socioeconomic status. All reviewed studies collected this type of information on participants. However, none of the reviewed studies reported findings linking these specific variables to perception of genetic risk and mate selection.

Genetic Testing-Related Factors

Genetic test-related factors represent 11.5% all findings in this review. Over three quarter (77.3%) of findings in this area revealed a negative association with perception of genetic risk and mate selection. Most of these findings were related to worry about stigmatization [3, 20, 23, 24], perception of the efficacy of genetic tests in reducing genetic disorders [4, 14, 18-20], and perception of accuracy of genetic testing [4, 5, 18, 19]. For example, increased worry about stigma due to higher perceived levels of genetic risk was associated with higher perceived likelihood of rejection by potential partners. Similarly, higher perceptions of genetic tests' efficacy led to lower perceptions of genetic risk and less conservative mate selection. Other test-related factors included cultural sensitivity of the genetic screening program [2, 18, 22], cost of genetic testing [4], testing as creating a "false sense of security" [4], knowledge concerning testing limitations [14, 22], and worry of loss of confidentiality [20].

Discussion

This systematic literature review appears to be one of the first to study an array of demographic, psychosocial, and testing factors that influence (i.e., mediate or moderate) the relationship between perception of genetic risk (one's own and a potential mate's) and mate selection. Previous reviews have explored these factors independently (Hallowell & Richards, 1997; Meiser et al., 2001; Simpson & Gangestad, 1992), or in combination with single variables such as intention to have genetic testing [5, 15]. This review further contributes to the literature by summarizing and describing factors related

to genetic risk perceptions and mate selection, and provides an analysis of the conceptual and methodological quality of the reviewed studies.

The current review identified almost 50 unique factors exerting an influence on the variables of interest (i.e., perception of genetic risk and mate selection). While the nature and type of influence differed, the largest number of findings involved bi-directional associations (n=77) between factors and the variables of interest. By 'bi-directional', we mean that as factors changed in strength or level, both positive and negative relationships (between the IV-DV) were identified in the same study. The remaining findings described positive (n=62) or negative associations (n=54). Higher number of bi-directional or inconclusive findings in this area may reflect the highly subjective and contextualized situations in which these types of risk-related decisions are being made.

When reviewed studies were analyzed for methodological quality based on study design (e.g., qualitative, quantitative, or mixed methods), differences emerged among the groups. Quantitative studies scored on average 12.0 points (SD= 2.4 points, Median=11.5, range=9-15 points), which was higher than other types of designs and over one half the standard deviation above the mean for all reviewed studies. Mixed methods study designs performed almost as well as the quantitative studies. On average, mixed methods studies scored 11 points (SD=2.4 points, Median=11 points, range=7-13). Qualitative studies exhibited the least variation in scores, however, the group only averaged 9.8 points (SD=1.4 points, Median=10 points, range=8-12 points) and almost one half standard deviation below the mean.

Differences in groups' average scores may have arisen due to an inherent bias within scoring criteria. While reviewed studies using quantitative data analysis techniques could receive as many as four MQS points, those using qualitative data analysis could receive only a maximum of two points. In other words, studies employing higher order quantitative analyses were awarded more points than studies using any form of qualitative analysis. Given that the MQS criteria have not been validated for application with the types of studies included in this review, average differences between study design groups may only be reflective of the scoring criteria's bias favoring quantitative studies.

Overall, the total mean MQS scores and range of reviewed study scores are indicative of room for improvement within this area of research. The highest ranked studies each received MQS of 15 (maximum MQS score= 20) [6, 16, 24]. These scores would have improved by providing operational definitions of the IV and DV, as well as using larger samples and mixed gender samples that included females under age 35. The lowest ranked study received a score of 7 points (minimum MQS score=4) [15]. This score would have been much higher if the researchers had provided operational definitions of the IV and DV, and used randomization with a larger and more diverse sample.

Rigorous research designs and methodologies that incorporate theory may prove vital in improving the overall methodological quality of these studies and possible replications. Based on the results of this review, the Health Belief Model (HBM) appears to be the dominant theoretical paradigm in this research area. Use of the HBM

may have been influenced by the fact that studies in this area are primarily published within medical, nursing, or health psychology journals. Other health behavior theories may have better predictive or explanatory power in terms of this relationship. Future studies should endeavor to explore this relationship between perception and mate selection using other theories. Grounded theory may prove particularly useful for exploratory studies of an underlying theory of perceived genetic risk and human mate selection. Recent advances in statistical modeling software such as structural equation modeling or hierarchical linear modeling may prove highly useful in testing existing theory or building new theory.

Limitations

While this review contributes a comprehensive picture of the factors affecting the relationship between perceived genetic risk and mate selection, it has several limitations. Our choice of search engines, for instance, represents one constraint: while Cambridge Scientific Abstracts (CSA) is an electronic database that provides access to thousands of indexed journals, other databases may index articles not available in CSA. As a result, articles may have been missed during the two search periods. In addition, the key search terms may not have been adequate to produce a truly representative number of articles related to perception of genetic risk and human mate selection. Additional search terms might yield more articles.

The purling technique also generates concern. Purling allows the reviewer to add studies to the final sample, at the risk of over-sampling authors. In the present review,

Raz [18-21] and McConkie-Rossel [15, 16] were first authors on several reviewed studies. Their combined scholarship accounted for 23.1% of studies in this systematic review. When their studies were removed from the sample, the mean MQS score improved by 0.3 points (mean=11.1, SD=2.2, skew=0.60).

A related question is how key associations between mediator or moderator variables and the variables of interest might change if multiple reviewed studies having the same first author were removed from the sample. For example, studies by Raz (and Raz and Atar) focused solely on the Bedouin population in the Middle East. Key findings of these studies include but are not limited to intention to have children, intention to get married, religion, consanguineous marriage, knowledge of genetic disorders based on "folk" wisdom, and views of abortion (independent of religious beliefs) as these variables relate to perceptions of genetic risk and mate selection.

Implications for Practice

Several of the reviewed studies demonstrated an association between perception of genetic risk, mate selection, and diminishing prevalence of specific autosomal recessive and dominant disorders. However, these studies were limited to a narrow range of genetic disorders, a number of which are often restricted to certain racial/ethnic groups (e.g., Cystic Fibrosis, Sickle Cell Disease, thalassemia, etc.). Future research should expand the types of genetic disorders considered for study. Expansion might increase racial/ethnic diversity within genetic studies of the IV-DV set.

Future studies should also continue to explore the demographic, psychosocial, and testing factors that influence the relationship between perception of genetic risk and mate selection. Exploratory studies that focus on young adult males and females of diverse racial and ethnic backgrounds prior to marriage and pregnancy would expand the literature. Such expansion would provide a solid foundation for health education and prevention-based programs.

CHAPTER III

"ROLLING THE DICE:" QUALITATIVE PHASE DATA OF THE PERCEPTION OF GENETIC RISK IN SEXUAL AND REPRODUCTIVE DECISION-MAKING (PGRID) BY COLLEGE STUDENTS STUDY

Introduction

Healthy People 2010 defines health literacy as the "degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (U.S. Department of Health and Human Services, 2000). Genetic literacy, a form of health literacy, may then be defined as the knowledge, skills and attitudes necessary to individual understanding of genetic information, and genetic-based health, behavior, technology and services (Johnson, Andrews, & Allard, 2001; Johnson, Case, Andrews, & Allard, 2005). This form of literacy is a vital component of sexual and reproductive decision-making. An individual who has attained some measure of genetic literacy should be able to critically evaluate genetic information; interpret personal risk; advocate for and access appropriate programs and services; and make informed decisions concerning his or her health-related behaviors and genetic health, including sexual and reproductive health (Johnson et al., 2001; Johnson et al., 2005).

This study was part of a larger, mixed methods research project that intends to answer the question "how does perception of genetic risk influence sexual and reproductive decision-making by college students, including mate selection?" Within

this broad, 'umbrella' question, this qualitative, exploratory study focuses specifically on two primary aims: to describe how a sample of young adults conceptualizes abstract ideas such as genetic risk; and to understand how individual perception of genetic risk influences sexual and reproductive decision-making, within this sample.

Theoretical Framework

Qualitative studies traditionally begin without *a priori* (preexisting) assumptions or theoretical frameworks. Instead, theory and corresponding variables emerge from data collected within the focal area (Lincoln & Guba, 1985; Strauss & Corbin, 1998). Theories created using this approach are "more likely to resemble the 'reality' of the data…(and) are likely to offer insight, enhance understanding, and provide a meaningful guide to action" (Strauss & Corbin 1998, p. 12). Given the highly subjective component of individual attitudes and beliefs, and their impact on behavior, qualitative inquiry provides powerful methods for uncovering beliefs related to genetics and the influence of these beliefs on indviduals' sexual and reproductive decision-making. Emerging qualitative content and themes may then be compared to existing theory and used to form theoretical models grounded in the data.

Selection of Research Paradigm and Rationale

According to Denzin and Lincoln (2000), individuals engaged in qualitative research "study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them" (p. 3). Qualitative

methods vary greatly in scope and complexity. Each method "makes the world visible in a different way" (pp. 3-4). As might be expected, varying the lens used to view the world is necessary when data take on radically different forms. Qualitative data is often harvested from personal narratives, observations, case studies, life histories, interviews, photographs, and any other audiovisual materials "that describe routine and problematic moments and meanings in individuals' lives" (p.3).

Individuals' attitudes and perceptions are highly subjective and have meaning that is particularly problematic to ascertain and to measure (Denzin & Lincoln, 2000). Qualitative analysis can reveal this meaning. Researchers in a number of disciplines are using qualitative and narrative analysis as a method for exploring *health-related theory, research and practice* (Harter, Japp, & Beck, 2005). Beyond analyzing the *linguistic* turn-of-phrase or the unspoken meaning, qualitative and narrative analysis also aid the researcher in discerning the "complexities that face contemporary health care participants: identity construction, order and disorder, autonomy and community, fixed and fluid experiences" (Harter et al., p. 8). In particular, illness narratives are useful for exploring how individuals understand complex concepts such as *health* and *genetic risk*, or communicate their subjective experience of an illness.

Trustworthiness (Issues of Data Reliability and Validity)

Issues of reliability and validity in qualitative research are often the center of debate (Riessman, 1993). Reliability relates to the researcher's ability to replicate findings. Validating qualitative data is "the process through which we make claims for

the trustworthiness of our interpretations" (Riessman, p. 65). Exploring the trustworthiness of qualitative findings involves evaluating interpretations for: *persuasiveness* of the arguments being made and accompanying support from the data; *correspondence* between what individuals or groups actually said and meant versus the researcher's interpretation; *coherence* between the researcher's interpretation and the data; and the future (pragmatic) uses of the interpreted data. While there is no one method for determining the validity of qualitative data, the present study will attempt to establish correspondence and coherence by presenting direct quotes from study participants and mirroring participants' language in interpreting study findings.

Researcher Perspective and Bias

The researcher is currently a doctoral student in health education at a university located in the Southwestern United States. Her interest in genetics began at an early age while assembling her family's genealogical history. While working on this project, she also documented the prevalence of various genetic disorders and multigenerational trends within her family. This formative experience stimulated additional interests in psychosocial, environmental, and behavioral determinants of health. To this end, she completed undergraduate and graduate-level training in biology and social work. As the researcher's early academic and professional preparation was firmly grounded in the quantitative, biological sciences, she is relatively new to the field of qualitative inquiry.

Her experiences as a graduate student represent her first forays into non-quantitative inquiry and methods. Particularly, she gained an understanding and

appreciation for qualitative methodologies' ability to uncover individuals' subjective reality, the subtle nuances often missed in quantitative exploration. Designing and implementing her mixed methods dissertation study increased her appreciation for all things qualitative. The results of this qualitative study were used to inform the creation of a web-based, quantitative survey, whose results will provide direction for future qualitative inquiry (see Chapter IV).

Method

Sample Selection

Each of the research sites provided Institutional Review Board approval to perform the study. This purposive sample of college students from three Southwestern U.S. universities consisted solely of currently enrolled students ages 18 and older (i.e., the only inclusion criteria for participation). Sites one and two were a majority Hispanic student-serving instiution and a majority minority and international student-serving instiution, respectively. Both were located in major metropolitan areas. Site three served a majority of Caucasian students with substantial minority and international student enrollment. This site was located in a rural county. Sites were selected because of existing professional relationships with university faculty and familiarity with university administration.

Participant recruitment consisted of IRB-approved flyers, advertisement with academic departments and student organizations, as well as personal contact with course instructors and classes. Most students who were approached via these channels agreed

to particpate in the study. Participants received food and/or movie tickets/gift cards in exchange for their time and participation in the study.

Instrument

The qualitative interview guide consisted of 15 open-ended questions and related probes (see Appendix B). Questions assessed how participants conceptualize abstract genetic concepts and employ genetic risk perceptions in sexual and reproductive decision-making. For logical flow and ease of understanding, the interview guide was divided into three sections: conceptualization of genetics, conceptualization of genetic risk, and operationalization of genetic risk in sexual and reproductive decision-making. This guide was piloted with a mock focus group of three health education graduate students (Site three) in July 2006. Based on positive feedback, no changes were made to the instrument prior to recruitment for this study.

Participants also completed a demographic data sheet containing questions related to age, marital status, race/ethnicity, religious preference, educational attainment, and other demographic variables. While participants were not asked to identify themselves in this information sheet, the form contained questions related to participants' exposure to genetic education, genalogical and health history charts, and prental testing. In addition, the sheet contained three questions modified from the 2004 *General Social Survey* assessing participants' knowledge of genetic disorders, access to information on genetic testing, and attitudes towards genetic screening.

Data Collection

Eight focus groups took place between February 2007 and February 2008. Site one hosted the first groups in February 2007 (n=2) and April 2007 (n=1). Site two hosted two groups in January 2008. The remaining groups were held at Site three in January 2008 (n=1) and February 2008 (n=2). Each focus group contained a minimum of ten and maximum of 13 participants. The researcher served as recruiter and moderator for these groups.

Prior to each focus group, participants reviewed and signed consent forms and completed demographic data sheets. The consent form contained contact information for study personnel, as well as for each site's student health center, counseling center and IRB in case participants experienced lingering feelings of discomfort related to participation in the study. The researcher then responded to participants' questions related to the consent form or participation in the study. Focus group interviews were audio taped to aid verbatim transcription; each group session lasted approximately 45 minutes. Each audiotaped session was then transcribed verbatim and transcripts were later analyzed for content and themes related to the research questions.

Data Analysis

The qualitative analysis employed in this study was modified from methodologies published by Daley and Onwuegbuzie (2004) and Lieblich, Tuval-Mashiach, and Zilber (1998). This modified *holistic-content* analysis process involved a 5-step process. First, the researcher read the narrative "several times until a pattern

emerge(d), usually in the form of foci" of the focus group transcripts (p. 62). After these initial readings, the researcher crafted an *initial and global impression* of the transcripts. The researcher then separated responses to questions in the interview guide into discrete *units* (themes). These units were grouped into clusters (factors) containing similar themes.

Steps three and four involved concentrating on content and themes of interest during their appearance, disappearance, and reappearance throughout the narratives (Lieblich et al., 1998). In step five, the researcher followed each theme and wrote conclusions based on *salience* to the overall narrative and major and minor themes' ability to address the major research questions. Descriptive analyses were also computed to assess frequencies of responses to questions on the demographic data sheet and interview guide (Daley & Onwuegbuzie, 2004). Frequency of themes was counted across interview transcripts for each question rather than aggregated across the entire study.

Results

Demographic Data Sheet

The sample (N=86) was diverse in terms of age, race/ethnicity, annual household income, and religious preference (See Table 4). Focus group participants ranged in age from 19 to 54 years of age (M=28.0 years, SD=8.1 years). Most participants were female (67.4%) and "White/Caucasian" (43%), "Hispanic/Latino" (29.1%), or "Black/African American" (14%). Their (or their parents') annual household incomes

ranged from $0 to $75,000+; most participants (57.7%) reported incomes of under $50,000 per year.

Of those who self-reported their religious preference, the majority of participants practiced a form of Christianity (88.1%). Participants who identified as Christian were "Catholic," "Christian, Other" or "Protestant." "Other" religious preference (11.9%) included "Agnostic," "Atheist," "Hinduism," "Judaism," and "None."

Focus group participants were currently enrolled students in educational leadership, engineering, health education, human resource development, kinesiology, nutrition/food science, or social work programs. Over one half (55.8%) were graduate (master's and doctoral) students. None of the participants were currently majoring in biology, genetics, or a related field; most participants (82.4%) had never taken a genetics course, mapped their family tree (55.8%), or charted their family health history (68.2%). However, the majority self-reported having taken at least one course containing genetic information as part of the curriculum (59.3%).

Participants also varied in terms of marital and parenting status and exposure to genetic information and services. While the majority of participants was "Single, Never Married" (74.4%), and did not have biological children (81.4%), almost one in five participants (18.6%), including a few who were "Single, Never Married," had biological children. Less than 6% of participants reported ever having undergone genetic testing and less than one fifth (16.7%) of female participants with biological children underwent prenatal testing during pregnancy.

Table 4. Focus Group Participant Demographics

Demographics	Site 1	Site 2	Site 3	All Sites
Gender				
Male	22	1	5	**28 (32.6%)**
Female	14	19	25	**58 (67.4%)**
Race/Ethnicity				
Asian/Pacific Islander	2	2	4	**8 (9.3%)**
Black/African American	3	6	3	**12 (14.0%)**
Hispanic/Latino	18	2	5	**25 (29.1%)**
White/Caucasian	11	9	17	**37 (43.0%)**
Other	2	1	1	**4 (4.7%)**
Average Age (SD; Range)	28.8 years (8.8 years; 19-54 years)	31.1 years (8.6 years; 19-50 years)	24.7 years (5.7 years; 19-44 years)	**28 years (8.1 years; 19-54 years)**
Marital Status				
Single, Never Married	24	13	27	**64 (74.4%)**
Divorced	1	1	1	**3 (3.5%)**
Married	11	5	2	**18 (20.9%)**
Widowed	0	1	0	**1 (1.2%)**
Have Biological Children?				
Yes	9	4	3	**16 (18.6%)**
No	27	16	27	**70 (81.4%)**
Religious Preference				
Catholicism	16	3	10	**29 (33.7%)**
Christian, Other	13	9	11	**33 (38.4%)**
Hinduism	0	2	0	**2 (2.3%)**
Judaism	0	0	1	**1 (1.2%)**
Protestant	2	2	3	**7 (8.1%)**
Other	4	4	4	**12 (14.0%)**
Current Educational Status				
Undergraduate	25	0	13	**38 (44.2%)**
Graduate	11	20	17	**48 (55.8%)**
Annual Income (Student's or Parent's)				
$0-$14,999	7	4	7	**18 (21.2%)**
$15,000-$29,999	8	3	7	**18 (21.2%)**
$30,000-$44,999	5	3	5	**13 (15.3%)**
$45,000-$59,999	2	2	1	**5 (5.9%)**
$60,000-$74,999	4	0	0	**4 (4.7%)**
$75,000+	10	7	10	**27 (31.8%)**
Highest Degree Earned				
GED/HS Diploma	17	0	11	**28 (32.9%)**
Associate's Degree	7	0	1	**8 (9.4%)**
Bachelor's Degree	2	17	4	**23 (27.1%)**
Master's Degree	10	3	13	**26 (30.6%)**

Most participants reported they never personally experienced genetic or prenatal testing (See Table 5). This finding was in line with self-reports that participants have read or heard "not very much" (84.5%) or "nothing at all" (9.5%) about genetic testing. In contrast, when asked if "genetic screening will do more good than harm, or more harm than good," participants' attitudes towards genetic screening were neutral or positive. Approximately one half (48.8%) of the sample believed that genetic screening "would do more good than harm" or "it depends." Fewer than 3% of the sample believed that genetic screening "would do more harm than good."

The demographic data sheet also presented a list of genetic disorders, non-genetic disorders (primarily birth defects), disorders having ambiguous genetic links, and health conditions due to gene-environment interaction (e.g., genomic disorders), and asked participants to identify with an "x" any "severe genetic disorders." Correctly identified genetic disorders included Down's syndrome (81.4%), cystic fibrosis (58.1%), sickle cell anemia (55.8%), muscular dystrophy (54.1%), and Huntington's chorea/disease (33.7%). Several non-genetic or genetic-linked health conditions were incorrectly classified as "serious genetic disorders." These included Spina Bifida (61.6%), mental retardation (50%), cerebral palsy (47.7%), multiple sclerosis (47.7%), bipolar disorder (15.1%), ADD/ADHD (11.6%), drug addiction (10.5%), and depression (9.3%). Almost one in five participants (19.8%) incorrectly identified HIV/AIDS as a "serious genetic disorder."

Table 5. Responses to Knowledge, Attitude, and Experience Questions

Knowledge, Attitudes, & Experiences				
	Site 1	**Site 2**	**Site 3**	**All Sites**
Ever had genetics course?				
Yes	2	5	8	**15 (17.6%)**
No	34	14	22	**70 (82.4%)**
Ever had course with genetics information?				
Yes	16	15	20	**51 (59.3%)**
No	20	4	10	**34 (39.5%)**
I Don't Know	0	1	0	**1 (1.2%)**
Ever charted family tree (genealogy)?				
Yes	14	12	11	**37 (43.0%)**
No	22	7	19	**48 (55.8%)**
I Don't Know	0	1	0	**1 (1.2%)**
Ever charted family health history?				
Yes	10	6	11	**27 (31.8%)**
No	26	13	19	**58 (68.2%)**
Ever had prenatal testing?				
Yes	2	1	1	**4 (5.9%)**
No	30	13	17	**60 (88.2%)**
I Don't Know	1	0	1	**2 (2.9%)**
I Do Not Want to Answer	1	1	0	**2 (2.9%)**
Ever had genetic testing?				
Yes	1	1	3	**5 (5.8%)**
No	33	19	26	**78 (90.7%)**
I Don't Know	2	0	1	**3 (3.5%)**
If you/your partner pregnant, would you want test for serious genetic disorders?				
Yes	22	15	19	**56 (68.3%)**
No	11	3	4	**18 (22.0%)**
I Don't Know	3	1	4	**8 (9.8%)**
How much have you heard or read about genetic testing?				
A Great Deal	0	3	2	**5 (6.0%)**
Not Very Much	31	17	23	**71 (84.5%)**
Nothing At All	4	0	4	**8 (9.5%)**
Do you think genetic screening will do…?				
More Good than Harm	22	10	9	**41 (48.8%)**
More Harm than Good	2	0	0	**2 (2.4%)**
It Depends	9	9	20	**38 (45.2%)**
I Don't Know	2	0	1	**3 (3.6%)**

Focus Group Interviews

As previously decribed, the interview guide was divided into three sections: conceptualization of genetics, conceptualization of genetic risk, and operationalization of genetic risk in sexual and reproductive decision-making. Below, findings are organized according to section and related questions (See Appendix B). For each question, indvidual themes and clusters are described and, when appropriate, illustrated with verbatim statements from participants. .

Conceptualization of Genetics

Defining the Term "Genetics"

Most participants were health and science majors, yet appeared hesitant to discuss genetic information (i.e., genetic concepts and processes; See Table 6). When asked to describe "what comes to mind" when the term "genetics" is mentioned, participants responded with genetic structures, terminology, and technologies or aspects of biological relationships (n=75 themes). Genetic concepts and technologies (n=59 themes) included "DNA," "genes," "chromosomes," "hair or eye color," "XX/XY," "dominant and recessive traits," "genetic diseases," "disorders," or "conditions," "genotype," "phenotype," "heredity," "science," "stem cells," and "cloning." In addition to genetic concepts and technologies, what came to mind for some participants were human biological relationships (n=16 themes). These relationships included "children," "parents," and "families" in general.

Table 6. Genetics: Summary of Findings and Clusters by Research Question

Focus Group Questions	Clusters	Themes
Q1. "When I say "genetics," what, if anything, comes to mind?" (n=75 themes)	*Genetics concepts & technologies (n=59 themes)*	DNA, genes, chromosomes, hair/eye color, XX/XY, dominant/recessive traits, science, stem cells, cloning, etc.
	Human biological relationships (n=16 themes)	family, children, parents, etc.
Q2. "What is 'genetic'?" (n=52 themes)	*Genetic characteristics and disorders define "genetic" (n=25 themes)*	"Colorblindness," "Cystic Fibrosis," "athletic ability," "bipolar," "depression," etc.
	Family as a genetic mechanism (n=17 themes)	"Inherited from someone above you," "runs in family," etc.
	DNA as Destiny (n=10 themes)	Predetermined, "hard to fix," "can't control," "predisposed," etc.
Q3. "Are some genetic disorders 'better' to have than others?" (n=77 themes)	*Manageability (n=19 themes)*	"some (disorders) more manageable than others"
	Prevention/Cure (n=8 themes)	"possibility of a cure," "prevention through lifestyle change"
	Lifespan/Development (n=7 themes)	"age (of onset) matters"
	Severity (n=6 themes)	some are "more severe"
	Debilitating effect on life (n=4 themes)	some are "less life debilitating"
	Impact on functioning (n=4 themes)	impact on "quality of life"
	Miscellaneous (n=29 themes; comparison of specific disorders)	Down's syndrome, diabetes, high cholesterol, Sickle Cell Anemia/Disease, etc.
Q4. "…where do you get genetic information?" (n=76 themes)	*Internet-based (online) resources (n=21 themes)*	"WebMD," "Google," etc.
	Parents and relatives as genetic information source (n=14 themes)	"mother," "parents," "aunt," etc.
	Health professionals as information source (n=14 themes)	"family doctor," "nurses," etc.
	Genetic health professional as information source (n=8 themes)	"geneticist," "genetic counselor," etc.
	Miscellaneous (n=19 themes; alternate genetic information sources)	"TV," "radio," "professors," "textbooks," etc.
Q5. "How do genetic traits manifest?" (n=61 themes)	*Individual or family factors (n=28 themes)*	"family history," "lifestyle," "spirituality," "socioeconomic level," etc.
	Gene-environment interactions (n=18 themes)	"chemicals," "food," "environment," etc.
	Miscellaneous (n=15 themes; perception and attitude factors)	"severity" of the disorder, "predisposing factors" (risk) for developing disorder," "preparation," "prevention," etc.

What Is "Genetic"?

The converse was true when participants were asked what is meant when an individual states, "an ability, behavior, characteristic, or problem is 'genetic'" (See Table 6). In lieu of referring to genetic structures and concepts, participants' responses primarily focused on the cluster of *DNA as destiny* and *family as a genetic mechanism* (n=52 themes). Genetic characteristics could be "good" or "not always negative;" however, these characteristics were "predetermined," uncontrollable, "hard to fix," and the product of a familial "predisposition" to some genetic health issue (n=10 themes). This predisposition was generally the result of characteristics "in the bloodline," "passed down" from one or both parents, or "inherited from someone above you (in the family line)" (n=17 themes). These "genetic" characteristics (n=9 themes) ranged from physical characteristics (e.g., "colorblindness," "Cystic Fibrosis," "body type," "inability to lose weight," "athletic ability," etc.) to emotional or mental health characteristics (i.e., "bipolar disorder," "depression," "personality factors," etc.).

Based on tone of voice and body language, participants were clearly uncomfortable discussing processes related to genetics; few responses yielded evidence that participants understood scientific mechanisms underlying genetic characteristics. Three participants mentioned "*DNA* mutations" as a factor in determining whether a characteristic was "genetic." Only one participant was able to identify biological mechanisms including "a missing gene or alteration of a gene" and "chromosomes (that) didn't match up or (…) chromosomes [that] didn't connect" (Male, Site 2).

How Do Genetic Traits Manifest?

When probed concerning factors that "may influence whether someone will manifest" a genetic characteristic, participants more readily identified *mechanisms* than static *concepts* (See Table 6). The most common responses centered on gene-environment interactions including exposure to elements within their "environment" (n=9 themes), "chemicals" (n=4 themes), "drugs" or "medication" (n=2 themes), "food" or "nutrition" (n=2 themes), and "stress" (n=1 finding).

Additional responses concerned individual or familial factors such as "phenotype" or "genotype" (n=7 themes), "lifestyle" or "behavior" (n=6 themes), "age" (n=4 themes), "family history" of a genetic disorder (n=4 themes), other illnesses (n=3 themes), "completely random" events (n=2 themes), "spirituality" (n=1), and "socioeconomic level" (n=1 themes). Only one focus group participant was able to discuss a genetic disorder in terms of its mechanism using scientific terminology and key concepts:

> It's a dominant or recessive character of ah, the, the base pair, the gene base pair, you have. For example, hemophilia would show up in the female if both the X have got the hemophilic factor, otherwise, in a male, even if one X has H, the male would show up to be hemophiliac. Females requires both the X to have H on them, otherwise, she may be the carrier, but she would not demonstrate the whole. (Male, Site 2)

No other participants utilized this depth of explanation related to factors influencing whether someone manifests genetic characteristics.

Non-biology-related responses to the previous question varied. For example, socioeconomic status was cited because "well, if you're poor you're not gonna have access to healthy food, the Internet or preventative (care), you know, (or) go to the doctor

if you're starting to get sick or any of those things" (Female, Site 1). Here, the participant refers to the concept that prevention-focused health care, dietary modification, and other lifestyle or environmental (e.g., economics, access to health services, etc.) factors may influence whether genetic traits manifest. In contrast, another participant identified spirituality as a possible influence. This participant (Female, Site 3) further explained her response by saying:

> I would say your spirituality because if you look at something like depression and how it manifests in, your spiritual life might help you cope, or may help you, someone said manage um, an everyday life.

In her case, she expects spiritual beliefs would aid coping ability, thus decreasing the likelihood that a genetic-linked disorder would manifest or reducing its impact on daily living. Based on these responses, rather than purely biological mechanisms, individual and environmental factors influence genetic expression.

Are Some Genetic Disorders "Better" Than Others?

Participants visibly appeared more relaxed when responding to the question "are some genetic disorders better to have than others?" (n=77 themes; See Table 6). A number of participants rated those genetic disorders that they perceived more "manageable" (n=19 themes), readily preventable or curable (n=8 themes), occurring "later in life" (n=7 themes), exhibiting lower "severity" (n=6 themes), less "debilitating" (n=4 themes), or having lower impact on individual functioning (n=4 themes) as "better." Specific examples included "diabetes," "high blood pressure," "high cholesterol," certain cancers, and, to a certain extent, "Sickle Cell Anemia" (i.e., because of its anti-malaria

properties). "Down's syndrome," "schizophrenia," "bipolar disorder," "Spina Bifida," consistently rated worse than disorders perceived to be more manageable or preventable.

Accessing Genetic Information

While participants varied in attitudes towards genetic disorders, they were more uniform regarding methods for accessing genetic information (See Table 6). When participants wanted genetic health information, they exhibited high health literacy in accessing health professionals, Internet technology, and traditional news sources for genetic information (n=76 themes). Internet (*online*) resources were the most commonly cited source for this type of information (n=21 themes). "Parents" or "relatives" (n=14 themes) and "nurses" or "physicians" (n=14 themes) were also common access points. Fewer participants reported using genetic health specialists (n=8 themes), "textbooks" or "journal articles" (n=7 themes), a "library" (n=3 themes), university "professors" (n=3 themes), "TV" or "radio" (n=2 themes), individuals "living with a genetic disorder" (n=2 themes), and "research" or charitable "foundations" dedicated to specific genetic disorders (n=2 themes).

Conceptualization of Genetic Risk

Defining the Term "Genetic Risk"

After responding to questions on genetics, participants were presented with questions related to the concept of "genetic risk" (See Table 7). Participants defined this

concept in a variety of ways. Some definitions were vague, "taking a big chance" or "the risk of inheriting something," whereas others relied on case studies to communicate their notions:

> My brother and his wife (are an example). Because um, of her earlier pregnancy, she was a carrier of this chromosome dysfunction factor, and if she were to pass it on, the high propensity for them to, you know, 50/50 chance, but they've had 2 subsequent children and they've had no problem. So that comes to mind with having that close to home. (Male, Site 1)

> I know a lady who they were telling her that she, her child wouldn't have it, wouldn't have this disorder, kind of, it was a brand new mutation it wasn't inherited, and so it was like one out of 70,000. So her first child had it, and she had a second child because she thought, you know, one out of 70,000, she's not gonna get it, and that's what the doctors told her, but she had another one with the disorder too. (Female, Site 2)

Approximately one half of themes (31 of 63 themes) in this area presented definitions of genetic risk in relation to decisions to have children. For example, one participant stated:

> I think there's a risk with anyone having kids because genetic disorders can happen to anyone. It doesn't matter if your family has it. (Female, Site 2)

Fewer participants conceptualized genetic risk in terms of dating or marrying (n=5 themes), age (n=3 themes), carrier status (n=3 themes), perceived severity (n=2 themes) or susceptibility (n=1) of the disorder, gender (n=1 themes), or personal experience with a genetic disorder (n=2). For example, when explaining age-related genetic risk, one participant (Female, Site 1) stated "I think that (there is an) elevated risk (for) women getting pregnant after, what is it in their forties, 45 (years old)?" Another

Table 7. Genetic Risk: Summary of Findings and Clusters by Research Question

Focus Group Questions	Clusters	Themes
Q6. "When I say the term "genetic risk," what, if anything, comes to mind?" (n=63 themes)	*Genetic risk in relation to childbearing (n=31 themes)*	"likelihood of getting" or "having a child with a trait" for a genetic disorder, etc.
	Perception of genetic risk (n=15 themes)	"high risk," "elevated risk," "the chance of (something) happening," etc.
	Risk factors influencing genetic risk (n=12 themes)	"age," "severity," carrier status," "personal experience" with an individual, etc.
	Genetic risk in relation to dating or marrying (n=5 themes)	"marrying someone with a risk," etc.
Q7. "How would you feel if someone in your family….?" (n=86 themes)	*Affective/emotion-based factors (n=40 themes)*	"scary," "nervous," "concerned," "worried," "stigma," negative impact on QoL of child/family, etc.
	Neutral attitudes towards "passing on" disorder (n=12 themes)	"it depends one the disorder," "it doesn't bother me," etc.
	Increased awareness and behavioral change related to the disorder (n=7 themes)	"be "more careful with lifestyle," get tested "and find out if I have it," etc.
	Family coping and acceptance(n=7 themes)	it's "just a part of the family," you "love them the same like any other family member," etc.
	Proximity of affected person in family line (n=6 themes)	"further back (in the line) wouldn't affect me," "more immediate (in the line) would affect," "if I had known (them) more when I was younger," etc.
	Risk taking (n=10 themes; positive attitudes towards genetic risk and decisions)	related to younger and older age (6), God/faith (3), and willingness to take risk (1)
	Risk aversive (n=2 themes)	"more careful in dating and marrying" and "more careful with having kids"
	Severity of the disorder (n=2 themes)	
Q8. "Which of the following make more sense and why….?" (n=69 themes)	*1 in 4 chance of developing a genetic disorder "makes more sense" (n=14 themes)*	"more clear," easier for visualization," "percentages don't have context," "less confusing," etc.
	25% chance of developing a genetic disorder "makes more sense" (n=13 themes)	"percentages are good and the focus is on risk for developing…the other seems backward," "represents the highest (possible) impact," "worst case," etc.
	75% chance of not developing a genetic disorder "makes more sense" (n=2 themes)	"the higher number is more deceptive," if person has "more optimistic" orientation, then they will receive "more comfort"
Which sounds more positive?	*75% chance of not developing a genetic disorder "sounds more positive" (n=9 themes)*	"the bigger (higher) number sounds better," "more optimistic," etc.
	1 in 4 chance "sounds more positive" (n=2 themes)	"less confusing," " "more up front," etc.
	3 in 4 chance of not developing "sounds more positive" (n=2 themes)	"bigger number sounds better," etc.
	25% chance "sounds more positive" (n=1 theme)	"more up front," etc.
Which sounds more negative?	*3 in 4 chance of not developing "sounds more negative" (n=7 themes)*	"too many numbers"
	25% chance "sounds more negative" (n=5 themes)	"you remember the smallest negative"
	1 in 4 chance "sounds more negative" (n=5 themes)	"if you get it (the disorder), you're not surprised," "smaller number sounds better," etc.
	75% chance of not developing "sounds more negative" (n=4 themes)	"sounds like the physician is hiding information," "if you get it (the disorder), you're surprised," etc.
	Answer choices are the same (n=5 themes)	

participant (Female, Site 1) responded to this statement with a gender-related risk "I was thinking I have a cousin who is a carrier for hemophilia and just the risk that she took in the possibility of having a boy but she ended up with two girls, but yeah just taking that risk."

Genetic Disorders Within the Family: "How Would You Feel?"

Participants then discussed their feelings if "someone in (their) family had a genetic disorder or a health problem related to genetics" (See Table 7). Their responses to this question were in line with previous responses linking genetic risk to reproduction (e.g., childbearing). Almost one half (n=40; 46.5%) of themes in this area were affective or emotion-based. A number of participants reported being "scared," "concerned," "depressed," "nervous," or "worried," if a genetic disorder were discovered within their family. They were especially concerned about the potential impact of this discovery on their and their children's "quality of life."

Conversely, participants from one focus group (Site 1) reported not being as concerned about their potential genetic risk due to being "younger" (n=4 themes) or guided by "faith" (n=3 themes). Those who were younger in age expressed belief that they were *risk takers*. One female participant admitted that she was more of a risk taker as a young adult because she was less knowledgeable about genetic health issues in her family; however, now that she is older, her perspective has changed considerably:

> When I was younger I heard people talking about hypertension and stroke and this and that and I really didn't know what it was until I started to go to the doctor and get physicals and then they started asking me about it do you have any history of this and this and this and I really didn't know, so I asked my mom and she was like yes, yes, yes. So, when I did that and then I realized, you know, I'm at risk for a lot of things…So when you're young you really don't see the difference …but now that I'm older it's really kinda scary, you know, am I gonna get diabetes or these things?…kind of weird. (Female, Site 1)

Participants who relied on religion or faith for guidance were "more willing" to take risks in childbearing:

> I think the biggest fear is when having children, it's okay, in my opinion, for me, it's okay if my child is different, if my child has Down's Syndrome, if my child has mental retardation. Is my child in some sort of physical pain on a regular basis? That's scary to me…Now, having a child who is you know, mentally a four year old for the rest of their life, you know, that's what God gave me. I just don't want them to hurt. (Female, Site 1)

Another female participant in this focus group stated, "what do I do with that information?" Is it going to stop me from wanting to have a child…it didn't and all of that, we kind of defaulted to the faith thing."

Other participants within the sample expressed that finding out someone in their family had a genetic disorder would increase their awareness concerning the disorder, and instill within them a desire to perform genetic testing, regular check-ups, or lifestyle changes (n=7 themes). Some participants qualified this change in awareness of personal genetic risk by speaking in terms of *proximity* (n=6 themes) of the disorder in the family tree and "severity" (n=2 themes) of the disorder. Proximity was defined in terms of "how close(ly)" the participant was biologically related to the affected relative. *Immediate*

relatives, grandparents, parents, siblings, aunts, uncles, and first cousins, were considered "close." The "closeness" of the relationship was also considered in terms of social interaction.

> A great cousin, you know, that I've never met, you know, that's not gonna affect me as much as a parent versus a grandparent or a sibling. (Female 1, Site 2)

> Kind of going off what she said, some disorders have physical um, symptoms and um, I think a sibling, I know my brother who looks a lot more like me, is more interested in genetic testing than my brother who doesn't, because there are some facial distinctions (of my genetic disorder). (Female 2, Site 2)

If immediate relatives, or more distal relatives with whom they had a personal relationship, were affected, participants were more likely to perceive an increase in their genetic risk. Their emotional proximity to an affected family member appears to influence genetic risk perceptions in ways similar to biological proximity. Thus, rather than a purely biological phenomenon, participants may conceptualize genetics across biological, affective, attitudinal, and perceptual domains.

Participants' perceptions of the severity of a genetic disorder also influenced their risk perceptions. The concept of severity related to where an individual's signs, symptoms, or level of impairment fell along a continuum. Perceptions of a disorder's severity ranged from not affected to completely disabled, and were highly subjective. Participants relied on their perceptions of severity to compare genetic and genetic-linked disorders and to assess genetic risk (i.e., their own, a potential partner's, future children's, etc.) for inheritance. For example, one participant (Site 3) weighed the severity of having sickle cell or a form of dwarfism versus that of Multiple Sclerosis or Down's syndrome.

Perceived severity of the disorder would aid in health decision-making including childbearing.

Genetic Numeracy: "Which Makes More Sense?"

Quantitative literacy (numeracy) may also have a role in health decision-making. Numeracy involves the increasingly complex range of skills necessary to perform mathematical calculations in everyday life (Kutner, Greenberg, Jin, & Paulsen, 2006). Medical and health professionals often operationalize genetic risk using numbers, particularly probabilities, percentages, and frequencies.

While participants provided concrete examples of types and severity of different genetic disorders, some struggled with numerical concepts (See Table 7). Participants were presented with four phrases (e.g., *25% chance of developing a genetic disorder, 1 in 4 chance of developing a genetic disorder, 75% chance of not developing a genetic disorder,* and *3 in 4 chance of not developing a genetic disorder*) and asked to discuss "which of these phrases makes more sense to you" and "why?" A number of participants expressed these options were quantitatively "the same," yet differed in terms of which phrases made more sense to them. Most participants selected "25% chance" (n=13 themes) and "1 in 4 chance" (n=14 themes) as the phrases that made the most sense. These positively worded options were viewed as "more concrete," "more memorable," "more up front," and "clearer." Conversely, the negatively worded options (e.g., "75% chance of *not* developing…" and "3 in 4 chance of *not* developing…") were viewed as "backward" and "confusing."

Participants often contradicted this concept when evaluating which phrases "sounded" more positive or negative. The "75% chance of not developing a genetic disorder" option was more often viewed as the phrase that sounded more positive (n=9 themes). Participants who expressed this belief reported that this phrase was more "optimistic" or provided "more comfort." Yet slightly more participants believed that the negatively worded phrases (chance of not developing a genetic disorder) sounded more negative than those that were positively worded. A few participants stated that, if their health care professional provided their risk assessment using "75% " or "3 in 4 chance of not developing a genetic disorder," they would feel that the individual was trying to "hide information," or "[be] deceptive" (n= 11 themes).

Based on these themes, all of the phrases made sense and evoked an affective response from participants. However, participants' understanding of their actual genetic risk was heavily dependent on their attitudinal orientation (e.g., "optimistic") and the manner in which genetic risk was contextualized:

> Also too, there's no parameters. One in four out of like, the world? One in four out of the United States? One in four out of Texas? I mean, because you talk about diabetes and you said, okay, one out of four in Idaho, okay, well that's a lot different than one out of four in San Antonio…It's, so the one out of four and the three-fourths, even the percentages, none of them, they have really no meaning except for maybe you said the 25% chance, but then you still have to nail down, you know, you know, what is that, what is that based upon? (Female, Site 1)

> Well it depends on what follows it. Like, for instance, if you were to tell me I have 75 percent, I'm sorry, 75% chance of having a healthy baby, that sounds good, but if you turn around and say you have a 75% chance of having, your baby having Down's Syndrome, that sounds bad. So it depends on really the context of what you're

> presenting. If you're presenting quote, unquote, good news, the bigger number sounds better. If you're presenting bad news, the smaller number sounds better. (Female, Site 3)

Information about context, meaning, or application was vital to reproductive decision-making (see earlier quotations from a male participant at site 1 and a female participant at Site 2).

Genetic Risk and Sexual and Reproductive Decision-making

General Factors Influencing Dating or Marriage

Participants clearly communicated their attitudes and beliefs when asked to interpret how genetic risk might influence their reproductive and sexual decision-making (See Table 8). For example, when asked "What types of factors would influence your decision to date or marry someone?," they reported a number of psychosocial and environmental factors. One hundred and eleven distinct themes were initially collapsed into ten clusters. The top five clusters involved *personality* (n=26), *genetic health* (n=17), *economic* (n=15), *social* (n=15), and *familial* (n=10) factors. Almost three quarters (74.8%) of themes were grouped into these clusters.

Personality factors included a potential dating or marital partner's "likes," "dislikes," and "ambition," and whether they were "fun," "like-minded," or "supportive." *Genetic health factors* (covered in greater detail later in the focus group interview), included whether or not the potential partner currently had a genetic disorder or genetic-related health issues, as well as his/her family genetic health history. Economic factors

Table 8. Genetic Risk and Sexual/Reproductive Decision-making.

Focus Group Questions	Clusters	Themes
Q9. General Factors Influencing Dating or Marriage (n=111 themes)	*Personality factors (n=26 themes)*	"attitude," "likes/dislikes," "ambition," ability to "compromise," etc.
	Genetic health factors (n=17 themes)	Cystic fibrosis, familial cancer history
	Economic factors (n=15 themes)	"financial potential," "money," "economic stability," "credit score," etc.
	Social factors (n=15 themes)	"similar (or different) ethnic background," etc.
	Familial factors (n=10) factors.	"values," reputation," "family background," etc.
	Religion/morality factors (n=8 themes)	"faith," "spirituality," "religious background," etc.
	Physical health/attractiveness factors (n=6 themes)	"looks," "physical attraction," "chemistry," "physical disability," etc.
	Mental health factors (n=5 themes)	"emotional disorders," "mental disorders," etc.
	Affective/emotional factors (n=3 themes)	"love"
	Child-related factors (n=1 theme)	"desire for children"
Q10. Health-related Factors Influencing Childbearing (n=60 themes)	*Genetic health factors (n=16 themes)*	seriousness (3), severity (2), Huntington's
	Mental/emotional health factors (n=14 themes)	"smoking," "heavy drug use," "mental health state," etc.
	General health factors (n=9 themes)	"Rh factor," "diabetes," "age," etc.
	Physical health factors (n=7 themes)	"physical disabilities," etc
	Child-related factors (n=7 themes)	"coping" skills, "get along with kids," etc.
	Financial resources/access to genetic and health care services (n=5 themes)	"financial" means, "access to health services" (to care for child if genetic disorder "passed on")
	Miscellaneous factors (n=2 themes)	"responsibility" and "purpose of life"

Table 8. Continued

Focus Group Questions	Clusters	Themes
Q11. Knowledge of Participants' Family Tree and Dating or Marriage (n=48 themes)	*Yes (n=9 themes)*	
	No (n=3 themes)	
	Yes, but not influence (n=3 themes)	
	Non-disclosure of family tree (n=2 themes)	
	Mental health factors (n=11 themes)	"bipolar disorder," schizophrenia," alcoholism," "anger management," etc.
	Genetic health factors (n= 8 themes)	"diabetes," "heart disease," "Huntington's", "random mutations," physical appearance and genetic health
	General health factors (n=2 themes)	"age"
	Affective/emotional factors (n=3 themes)	"inner strength," "beauty," and good personality
	"Nature" vs. the familial environment (n=2 themes)	"familial traits" and home life
	Prevention (n=2 themes)	"abortion" vs. "adoption"
	Severity of the disorder (n=2 themes)	
	Economic factor (n=1 theme)	"educational level"

Table 8. Continued

Focus Group Questions	Clusters	Themes
Q12. Knowledge of Participants' Family Tree and Childbearing (n=34 themes)	*Risk takers (n=13 themes)*	preparation/life style change (1), "influence, but not decide" (2), severity (2), with genetic testing (3), etc.
	Risk aversive (n=21 themes)	preparation (3), severity (1), seriousness (1), adoption (3), proximity (1), decreased QoL (1), Sickle Cell Anemia (1), Hemophilia (1), etc.
Q13. Knowledge of Potential Partner's Family Tree and Dating or Marriage (n=46 themes)	*Yes (n=2 themes)*	
	No (n=2 themes)	
	Did not consider previously in relationships (n=5 themes)	
	Neutral (n=1 theme)	pro-disclosure
	Risk takers (n=20 themes)	seriousness (4), severity (4), proximity (2), timing (1), coping ability (1), preparation (1), love (2), compatibility (1),
	Risk aversive (n=16 themes)	mental disorders (5), breast cancer (1), domestic violence (1), drugs/alcohol abuse (2), QoL of family/kids(2), adopt (2), date but not marry (1), etc.
Q14. Knowledge of Potential Partner's Family Tree and Childbearing (n=30 themes)	*Risk takers (n=17 themes)*	love (3), preparation (2), coping/acceptance (2), seriousness of relationship (1), female gender (1), age (1), prevention (1), family traits (1), etc.
	Risk aversive (n=13 themes)	coping (1), QoL for child/family (1), negative attitude toward pregnancy (1), negative attitude toward abortion (1), severity (2), Down's syndrome, autism, etc.
Q15. "Where do we draw the line? (n=97 themes)	*Negative attitudes towards genetic technology* (n=47 themes)	eugenics movement imagery, "mail order kid"
	Neutral attitudes towards genetic technology (n=19 themes	alternating positive and negative attitudes
	Positive attitudes towards genetic technology (n=18 themes)	preparation, potential cures
	Popular media as genetic information source (n=9)	GATTACA, Jurassic Park, etc.
	Genetic health and technology policy (n=4 themes)	Role of insurance, federal government

centered primarily on whether an individual had "finanical potential," "educational level" (to secure a well paying position), "money" or "economic status," and was currently employed ("job"). Social factors were related to having "similar interests" and "goals" or "hobbies," and membership within a specific ethnic or cultural group. Familial factors focused on "family background," "structure," "values," and "reputation." The remaining themes were related to *religon/morality* (n=8), *physical health/attractiveness* (n=6), *mental health* (n=5), *emotional* (n=3) and *child-related* (n=1) factors.

Health-related Factors Influencing Childbearing

A number of health-related factors were identified as influencing participants' "decision to have children with someone" (See Table 8). Sixty distinct themes were initially collapsed into seven clusters. The top three clusters involved *genetic health* (n=16), *mental/emotional health* (n=14), and *general health* (n=9) factors. Almost two thirds (65%) of themes were grouped into these clusters.

Genetic health factors included positive and negative statements concerning participants' willingness to have children with someone who had a genetic disorder. Perceived seriousness (n=3 themes) or severity (n=2 themes) of a partner's (or their own) disorder exerted an influence on this type of decision:

> If they are susceptible to a genetic disease, what, how serious is that, like disease or condition. Like, is it something that could be fixed or is it something that there's no way it can be fixed, is it going to be a serious debilitation to the child and just factors like that. (Female, Site 3)

> Um, you know, I'm prone to have diabetes, you know, I hope my future wife doesn't have diabetes. You know, my whole family has diabetes, so it's like, I don't want to marry someone that has diabetes and our children will have diabetes from the age of one. I've seen how that goes…it's just not something I want to put my partner through or my child through. So yes, I would be a little more particular. (Male, Site 1)

Based on their perceptions, participants would decide whether to have biological children or to consider alernatives:

> Um, I think as far as genetics and reproducing though, if I looked at someone and said oh they have cystic fibrosis, I would just maybe think of another method of maybe adopting or some other way to have kids…(Female 1, Site 2)

> I was just gonna say, I think I would probably, um, I want to date someone, because I have a 50% at least chance (of passing on my genetic disorder), um, I know I'm not gonna have children, therefore, that person needs to understand that. And so, I mean, if you're dating someone who has a genetic abnormality, that's definitely something to go, 'are you going to have children?' You know, it may be based on, input on their decision and they're just an equal partner on it, but they may have already decided whether they want to or not, based on their genetics. (Female, Site 2)

Participants also expressed primarily negative attitudes towards having children with individuals with mental/emotional health issues (n=14 themes). Some participants were vague, using only the phrases "mental health" or "emotional health." Others specifically named "alcoholism," tobacco usage (e.g., "smoking"), and "heavy drug abuse"/"use" as strong factors in this type of decision. Only one participant stated that a partner's mental health status "would not influence" her decision to have children with

them. More general health factors included "personal health," "blood Rh factor," "age" at time of childbearing (also referred to as "timing"), "diabetes," and communicable disease status (e.g., "HIV status," etc.).

The remaining clusters of themes included *physical health* (n=7), *child-related* (n=7), *financial resources/access to genetic and health care services* (n=5), and miscellaneous (n=2) factors. A potential co-parent's physical health was considered important as it related to the presence or absence of physical disabilities. Male and female participants expressed beliefs that physical disabilities might impair their partner's ability to be a successful partner or parent. They also expressed doubts concerning their own abilities to care for someone with a physical disability and make necessary "life adjustments."

Child-related factors included co-parent characteristics such as their "desire for children," and whether they were "good with children," could "cope" with "passing on" a disorder to their children, and be a "good caretaker." The child's quality of life was included in this factor. (Financial resources and access to genetic and health care services was a separate, but related extension of this cluster.) Miscellaneous factors included whether the potential co-parent has a general sense of responsibility and a "purpose of life."

Knowledge of Participants' Family Tree and Dating or Marriage

Participants were then questioned how knowledge of their family tree or history would influence a potential partner's decision to date or marry *them* (n=48 themes; See

Table 8). A number of participants responded "yes" (n=9 themes) or "no" (n=3 themes) based on a rapid assessment of their family history and genetic risk perceptions, but did not elaborate (n=12 themes). A few other participants responded "yes," and then indicated that this information would "influence but not change" a potential partner's decision (n=3 themes).

When probed concerning specific ways that a participant's family tree might inform a potential partner's decision-making, several participants referred to familial histories of specific mental disorders (n=9 themes). Based on their responses, genetically influenced types of mental/emotional disorders such as "alcoholism," "bipolar disorder," and "schizophrenia" would be potential deterrents:

> Yeah, if you was, maybe had some bi-polar, schizophrenia, you think that man would think a second about marrying you? Yeah! (Female, Site 2)

> They'd go running the other way…Girl, I would be sitting at that house every Friday, every Saturday if they knew too much about my family tree…I mean, not with, overt, genetic disorder, but like, with just some of the things, some of the personality traits that are displayed in my family…The mental disorders…I mean, that would really, it would really give them some reason to pause I think. (Female, Site 2)

> …I've never been faced with that situation, but talking to my sister specifically who is bipolar, there have been countless times we've had conversations about 'well I have to tell him that I'm bipolar, like, obviously that's something that he's gonna need to know.' And it's never just a 'oh yeah I'm bipolar, so what do you want to have for dinner?' It's, like, we have to sit down and have, she has to sit down and have a conversation about it because it is something that does run in our family and it is something that could potentially affect children or anything in the future. (Female, Site 3)

Fewer participants in the sample believed that potential partners would do more than assess: 1) the severity of their genetic-linked mental disorder (n=2 finding), or 2) their current mental health status and level of coping with the disorder (n=1 finding) prior to dating and marriage decisions.

Participants reported that potential partners' perceptions of mental disorders and the potential impact of these disorders on future quality of life may influence dating or marriage decisions:

> …just because you don't have it (symptoms) now, what about later in life? You think about the burden of dealing with a wife, that has these uh, mental issues. (Male, Site 1)

While some expressed doubts, a few participants in the sample indicated that their more positive qualities, combined with "love" and a desire to "cope" with the disorder, might ease potential partners' concerns about their future. Some of these qualities included "inner strength," "beauty," and good personality (emotional and personality factors, n=3 themes).

If possessing positive personality traits were not enough of an incentive for potential partners, some participants would consider alternatives strategies. Two participants discussed genetic disclosure in the dating process. One participant (Female, Site 1) reported that she would circumvent a potential partner's decision-making process by failing to disclose negative aspects of her family health history.

> You asked a question about if someone knew that you had a genetic disorder in your family and it's like then you would need some sort of disclosure, right? Because if you're dating somebody if I know have debilitating genetic problem in my family, do I want to tell this person I'm with for fear that they may not want to be with me? Maybe

> if I love this person so much, I might not want to tell them and just pretend like 'how did that (a child being born with a genetic disorder) happen?' You know, you just might not want to say.

Similarly, a participant (Female, Site 3) from another group stated:

> But what happens if you already fall in love with that person and you're madly in love and you want to be with that person and then later you find out about all those little secrets? I guess that tests your love for that person.

Based on participant responses in this area, use of deception in dating appears to provide participants with the appearance of having a more positive genetic risk profile than their actual level of personal or familial risk.

Additional factors related to potential partner's dating or marital decision-making included genetic health (n=8 themes), general health (n=2) and economic factors (n=1 finding). In this case, genetic health factors would include themes such as "random mutations," and familial history of Huntington's disease, diabetes, or heart disease. Age and educational level were the sole themes for general health and economic factors, respectively.

Knowledge of Participants' Family Tree and Childbearing

Beginning with the earlier question concerning health-related factors influencing childbearing, an interesting dynamic became apparent during the course of the focus group sessions: participants began slowly dividing into camps concerning risk-bearing decisions. At first, this tension was subtle. However, as the sessions progressed, participants further divided in terms of sexual and reproductive decision-making. When

asked to describe how knowledge of their family tree would impact their decision to have children, conflict emerged between those who would and would not have children based on perceived genetic risk (n=34 themes; See Table 8). The following exchange between focus group participants embodied this growing conflict:

> And I'm a God fearing human being and I believe in fate, like, I want my children, I pray that my children are gonna be healthy, but if I was told there hey, there's an 80% chance, you know, God made children who don't have parents available too. So it just, I don't see why parents would do that. Because there are parents who say I'm gonna have kids no matter what! (Male, Site 1)
>
> Well I think it's easier for you to say that because, if I'm not mistaken, you don't have kids, right? (Female, Site 1)
>
> No, I don't have kids. (Male, Site 1)
>
> Okay, being a woman that does have kids and they're teenagers, and um, knowing my family history, I would still have a child because I think we run the risk every single day, even when you get behind the wheel. You run the risk all the time. Now, if I was pregnant and I did the testing and I found out, you know, the genetic disorder or what not, and I had the choice to terminate, I probably wouldn't. I'm confident about that. I would take whatever is given to me. I'm a believer that I'm always given what I can handle, no matter what. You know, and being a mom, it's harder for me to say no, I can't deal with this, because I've already done it with two kids (Female, Site 1)

Differences in childbearing decisions appeared to be influenced by the above-quoted participants' religious or spiritual beliefs, desire for biological children (versus willingness to adopt), and orientation towards risk-taking. Thus, both participants in the previous quotations expressed religious or spiritual beliefs, yet their beliefs resulted in very different attitudes towards potentially "passing on" a genetic disorder to their children. For example, those in the sample who were more risk averse expressed

preferences to adopt, depending on the genetic disorders proximity in the family line, severity, and potential impact on child's quality of life. Whereas, those who were more favorable to risk-taking indicated that they would concentrate on preparation for parenting a child with a potential genetic disorder.

Knowledge of Potential Partner's Family Tree and Dating or Marriage

Participants continued to be divided in terms of whether knowledge of a potential partner's family health history would influence the decision to date or marry them (n=46 themes; See Table 8). When questioned concerning this decision, two participants simply responded "yes" and two participants responded "no." When probed further, more participants were favorable to risk taking (n=20 themes) than were risk aversive (n=16 themes). Risk takers were those participants who weighed the decision based on seriousness (n=4 themes) or severity of the disorder (n=4 themes), proximity (n=2 themes), preparation (n=1 theme), and coping ability (n=1 themes). Additional non-health-related themes included "timing" of the relationship (n=1), "compatibility" (n=1), and "love" (n=2). One female participant (Site 3) explained the decision in the following manner:

> … I don't think that if I met someone and they said 'oh by the way I have this disorder in my family' that I'd say 'no thank you and goodbye.' I mean, it would be, for me, okay that's fine, we work through it and if I, I would still date a person like, like that, I guess you would say. I would still date a person, we all have a family health history, I mean, there's always something, that's just the way that it is, so I don't think that would keep me from dating someone and if it got to the point where we were serious in our relationship I don't think it would keep me from marrying them if I feel like I love the person and everything else was right…because yeah, it's one more thing that we

> have to worry about but I think that it's possible to work with it and manage it and do what you need to do to figure it out. (Female, Site 3)

Another female participant in the same focus group clarified this distinction by saying:

> I think this question is more of a consideration when you're thinking about getting married because then your implications of whether or not you're gonna have kids, what might happen. So I think at the dating stage I, I wouldn't really think about it unless you foresee that relationship going places. (Female, Site 3)

Decisions to date or marry appear to be qualitatively different. As relationships strengthen and partners begin to consider marriage and childbearing, genetic risk becomes more of a consideration, whereas casual dating may not invite the same introspection and risk assessment. For those who are risk takers, this risk may not play as prominent a role as compatibility, love, or coping, in these decisions.

In contrast, several participants who were risk aversive reported that they were less likely to (or would not) date or marry individuals having mental disorders (n=5 themes), drug or alcohol dependence (n=2 themes), or similar familial risk for breast cancer (n=1 theme). The following quotation embodies elements of the risk aversive perspective:

> It would definitely influence. Just because, I mean, there are certain, it depends on what the disorder/disease, whatever it was, my view of how severe that is. Because I, I look at my cousin, who has the autistic child and I think to myself that for the rest of her life she's probably going to have to take care of this person…You know, if I were to have a child now, I'm 32, and (when) my child is 32 and I'm 64, and still care for an adult, somebody as big as me. If I knew that there was definitely a possibility of that, with that particular man, and it was on the verge of dating, I would say no. (Female, Site 2)

While risk taking and risk aversive individuals explore issues of severity or seriousness, those who are risk aversive appear to emphasize the more negative aspects of an individual or family's genetic risk in their decision-making.

Non health-related factors would include familial (n=1 theme) and child-related (n=2 themes). Specifically, risk aversive participants reported that they would be less likely to date or marry someone who experienced domestic violence in their family of origin. They would also assess the potential impact of a disorder on their quality of life and/or opt to adopt in lieu of having biological children with specific partners.

Knowledge of Potential Partner's Family Tree and Childbearing

When asked how a potential partner's family tree might affect their decision-making, participants maintained division between those who were risk takers (n=17 themes) and those who were risk aversive (n=13 themes; See Table 8). Those who were more likely to take risks in childbearing evaluated social, emotional, child-related, general health and genetic health factors in making pro-childbearing decisions. Specifically, emerging themes in this area included love (n=3), preparation for (n=2) and coping/acceptance pertaining to "passing on" a genetic disorder to children (n=2), seriousness of the couple's relationship (n=1), female gender (n=1), and age (n=1). One participant (Site 2) who has an affected family member expressed the following sentiments related to childbearing decisions:

> …I have a cousin with Angelman syndrome, which no one has ever heard of…It's really severe, I mean, he has no language capability or whatever, but he's such a blessing to their family. And it wasn't something that they expected and it's a genetic disorder. But it's just, he's a part of our family. And you know, if I had a kid with that same thing, it's just you go with it. No one else in my family has it except him and so nobody expected it. But that's just who they are. If your child has autism or ADD or Down's Syndrome, they're your kid, you know? (Female, Site 2)

This participant would make childbearing decisions and accept the outcome if her child were affected by a genetic disorder. Another participant (Site 1) reported that he would make his decision using a different rationale:

> I'll take the risk (having children). I want to do it. Like, I've always wanted to marry some tall, big woman, you know? [group laughing]…No, I want my kids to play football!… (I'm) like 5'9" – I played football and I was linebacker, but I was always 5'9" and like when I was playing football everyone always said if I was like an inch taller I would be playing college ball right now, but you know I was small, so I want to be with a really tall girl (and have children), you know? (Male, Site 1)

This participant would take childbearing risks based on his perceptions of the potential outcome and its impact on quality of life.

Similarly, participants who were risk aversive were also concerned with issues related to quality of life. However, their focus was on the more negative aspects of childbearing in relation to genetic risk. Risk aversive participants assessed child-related and genetic health factors in making these decisions. Specifically, emerging themes in this area included the perceived severity of the genetic disorder (n=2), inability to cope with "passing on" a genetic disorder (n=1), lower perceived quality of life for the child and family (n=1), and negative attitudes towards pregnancy (n=1) and abortion

("termination," n=1) of an affected fetus. Further, those who were risk averse spoke more negatively, specifically in terms of "passing on" genetic disorders such as Down's syndrome or genetic-linked disorders such as Autism. For example, one participant (Site 2) who has an affected family member expressed the following sentiments related to childbearing decisions:

> And I would deal with (my child having a genetic disorder) it if it was like, a surprise (pregnancy). But if it was not a surprise, if I know what's coming, no, I wouldn't choose that pain, I wouldn't choose it. (Female, Site 2)

Another participant mirrored this sentiment:

> What's important is also how much I or my husband want to have our own children because if we're both fine with not passing on our heritage we can adopt, but if one of us wants to have our own children, um, we will have some serious discussions. (Female, Site 3)

Genetic Technology: "Where Do We Draw the Line?"

Responses to the final question, "do you foresee any benefits or problems that might occur because of highly advanced genetic technology?" revealed several clusters corresponding to sexual and reproductive decision-making (See Table 8). Whereas previous responses focused on emotional, social, economic, or health-related factors, emerging clusters in this area focused almost exclusively on participants' attitudes towards genetic technology. Ninety-seven distinct themes were initially collapsed into five clusters. These clusters involved *negative attitudes towards genetic technology* (n=47 themes), *neutral attitudes towards genetic technology* (n=19 themes; i.e., attitudes based on "it depends"), *positive attitudes towards genetic technology* (n=18 themes),

popular media as genetic information source (n=9), and *genetic health and technology policy* (n=4 themes) factors.

Negative attitudes towards genetic technology (n=47 themes) formed the largest cluster. Participants who shared this viewpoint were very expressive in rejecting classic imagery associated with earlier eugenics movements and their accompanying emphasis on certain physical and mental qualities (e.g., blonde hair, blue eyes). They often referred to genetic engineering technology in terms of producing a "mail order kid," or being similar to "shopping" or "building a car." As with "build to order" products, these participants expressed fears that individuals having lower incomes or lacking health insurance would be unable to take advantage of genetic technologies' perceived benefits. Participants expressed this concern by stating:

> Everyone wants their blue eyes, blonde hair, you know, perfect Brad Pitt looking child, but no, I'm just saying is what it's gonna come down to is the people with the money are going to be able to do this. And there's always gonna be, you're not gonna see the underprivileged people choosing their child with blue eyes and stuff so it's gonna, it's gonna be a big mess. (Female, Site 3)

> I think money is going to play a big factor in that, because you know, if you have no money you're not gonna be able to pick what child you have, as it stands now, you know? But if you have the money and you want a child with red hair, and you're able to pay for it, then (you'll get it). (Female 2, Site 2)

Further, participants with negative attitudes towards genetic technology reported concerns that this technology was incompatible with their "religious," "spiritual," and "moral" beliefs. Several participants rejected use of genetic technology, equating its use with "playing God" or "messing with Mother Nature." Additional participants who

shared this philosophy rejected the technology because they felt it might lead to "side effects" or unnecessary abortions:

> I always wonder if they're going to make this perfect, like you said, Miss America or whatever and then she turns out to be a bitch somehow. (Female, Site 3)

> And if it's not natural to select the sex of your baby and like you said eye color and stuff like that. But like where does (it) stop to where you're just picking exactly what your child is going to be like? Then if people do know, eventually will every child that is determined to have a learning disability, like will they terminate those pregnancies, like, more often because they know about that? I mean, I don't know, it's kind of scary I think. (Female, Site 2)

> I was gonna make that same comment, just the fact that for some people, if you hear your baby's gonna have Down's Syndrome, it might be like, ok that's it, like, I don't want to go through with it… Like, there are people that can't get pregnant, …if it gets to the point where it's being treated as something that's so nonchalant and commonplace well oh, this baby I'm gonna have is gonna have Down's Syndrome we'll just pick another one, we'll just pick another one, design my own little thing. And so I think that it's good in if people take it with the information of yes, now I can prepare for this and I can be better equipped to handle the situation, but if it gets to the point where it's, you know, every time you turn around and someone gets told they're gonna have a baby with a genetic disorder the first option is termination (then no). (Female, Site 3)

In contrast, some participants expressed positive attitudes concerning genetic technology. Participants who shared this viewpoint were very expressive in emphasizing the role of this technology in helping couples to *prepare* for parenting children with genetic disorders. Additional benefits of this technology included improved knowledge of specific genetic disorders and research concerning treatment and potential "cures":

> …if you find out that there's this genetic disorder that they (your child) might have that you know nothing about and you've never heard of it, then you have all this time (during pregnancy) to research it and be knowledgeable about it prior to, you know, the child being born. (Male, Site 1)

> I think there's a benefit because (garbled) like HIV and AIDS you there's people are having, that have it, and are still having children so it's (garbled) occurring and it gets bigger and bigger. So if you can somehow stop that by genetically engineering, you know seeing that ahead of time and being able to reduce the spread (of HIV). (Female, Site 1)

> I think it would be good in some aspects um, like in helping you prepare for your child if, you know, if, you found out later into your pregnancy term that there was going to be some type of learning disability or some type of physical disability that wasn't found out until later in your pregnancy, you know, it would help you to prepare, you could learn more about how to care for your baby in that aspect, um, and that would be, I think, an advantage. (Female, Site 3)

Not all participants expressed exclusively positive or negative attitudes towards genetic technology. Some participants alternated between negative and positive attitudes towards genetic technology, often within the same statement. The following statements provide examples of this:

> So my post conception (genetic testing), I see sickle cell anemia and I select that out heck yea, that'd be great, move that out…for things that are debilitating on the quality of life I see a lot of benefit. But random, I want a blue-eyed baby, I don't agree with (that). (Female, Site 3)

> I would, I'm not gonna abort my child, ever, and that would be my belief and other people may not believe that way but I would never abort my child no matter what the condition was, right. But then again with science being the way it is with them being able to detect that problem, maybe they can do something, maybe make it less of a problem while the child is growing as opposed to when it is fully developed and out of the womb. (Female, Site 1)

Popular media as a genetic information source and policy were the remaining clusters in this topic. Several participants utilized examples from popular media (e.g., *GATTACA, Jurassic Park, I Am Legend*, the book *Brave New World*, and the television show *CSI*) in order to describe the influence of genetics and genetic risk. Additional participants referred to the Discovery and History cable channels, and books, in referencing aspects of genetic technology.

Participants also drew material from movies and television programs to illustrate their perceived need for genetic health policy. While they did not describe the exact parameters of this type of policy, participants did express concerns for what might happen without public protections in this area. The following exchange illustrates this belief:

> Eh, yeah, I'm sorry. Uh, where it might get to the point where like, you've got government or like, insurance companies coming in and saying we're gonna be doing this then that's getting to that person right there, like she was saying too, but that's a whole different thing, I think, when you have like, to consider the whole society as opposed to my kid, what do I want for my kid. (Female 1, Site 3)

> But what about the culture that they like boys then they're gonna get boys, they got no girls and they're gonna die out in a couple generations or something like that? (Female 2, Site 3)

> They'll kill each other first. (Female 3, Site 3)

> Or you're just gonna have to, you have a sick kid, we're not gonna pay, we're not gonna cover that. That uh, we know, insurance companies, they do stuff based on race. They know that if you're gonna have something, I'm not gonna cover you, then again that's where the government is gonna come in. I'm here to make money, I'm not here to help you. (Female 1, Site 3)

> It seems like releasing that kind of information can be really dangerous because once people get that information in their hands, then they start using it and you don't know how everybody's gonna use it. (Female 4, Site 3)

Discussion

Currently, Hollywood movies, television, and other popular media exert an incalculable influence on the way that individuals understand genetic terms, concepts, and processes (Nelkin & Lindee, 1997). In drawing from popular media, focus group participants were able to synthesize knowledge of concepts and communicate their findings using examples that were readily accessible to their peers. Overall, participants exhibited a moderate level of verbal and knowledge-based health literacy when interpreting and discussing genetic risk information, even when they were unfamiliar with their mechanisms. For example, participants were able to discuss different types of genetic disorders such as Down's syndrome, Sickle Cell Disease, and Hemophilia, as well as factors that contribute to their manifestation and inheritability.

Yet, this information periodically contained inaccuracies. Participants sometimes attributed individual characteristics to genetic inheritance. The "linebacker" response to a childbearing question provides a strong illustration of this fallacy as do responses attributing other athletic abilities or personality, to purely genetic traits.

Further, participants misinterpreted numerical genetic risk, seeing this concept more in terms of absolute risk rather than as a fluid, changing, and complex calculation. Their risk perceptions and understanding of this information appear to be grounded more in highly contextualized personal, familial, or social narratives than in the scientific

literature. This numeracy issue may be particularly troublesome for participants who may have strong emotional responses to genetic issues due to personal or familial experiences. (Over one quarter [26.7%] of participants reported that they, a close friend, or relative were affected by genetic disorders.)

Thus, numeracy may not influence actual risk-bearing decisions to the same extent as perceptions of the severity or seriousness of the genetic disorder and perceived risk to potential children. These perceptions are sometimes linked to what people have seen in others, or experienced themselves. If, for instance, an individual is exposed to someone during a pro-dromal (asymptomatic) period of a genetic or genetic-linked disorder (e.g., Huntington's, bipolar disorder, schizophrenia, etc.), his or her initial impressions of this disorder may be that the disorder is not "severe." Or, they may perceive that the condition is not as severe as a "more visible" genetic disorder such as Down's syndrome. Misinformation and inaccurate perceptions may later lead to inappropriate sexual and reproductive choices.

This fallacy may not be limited to those with personal experiences with genetic disorders. As demonstrated previously, movies and television programs may influence perceptions. For example, impressions given by the movie *A Beautiful Mind* may lend themselves to more positive or negative perceptions concerning the severity and seriousness of schizophrenia.

When combined with social, emotional, and health factors, experiences or relationships with those living with a genetic disorder may also influence knowledge and attitudes towards genetic disorders and technology. By far, participants' attitudes

towards genetic technology were negative; however, a number of participants expressed neutral or ambivalent attitudes. Part of this duality in attitudes may be the results of opposing personal and academic or professional views. A large number of participants were graduate-level students in health education, kinesiology, social work, or a science/engineering-field. They were also part of a predominately-Christian sample.

Overall, responses to focus group questions provide evidence that participants *do* incorporate perceptions of genetic risk into sexual and reproductive decision-making. Participants were able to describe the often-conflicting psychosocial and contextual factors that contribute to these types of decisions. Diversity in participants' age, gender, race/ethnicity, marital status, religious preference, and exposure to genetic concepts and technology, as well as social, emotional, economic, and health factors, appear to influence whether individuals become risk takers or risk aversive in these types of sexual and reproductive decisions.

Limitations of the Study

This study had several limitations including purposive sampling, and inability to categorize individual participant responses by common demographic characteristics (e.g., age, race/ethncity, religious preference, etc.) or to record frequencies when multiple persons agreed or disagreed with a speaker's comments, due to the focus group format. Issues of generalizability are usually not the purview of qualitative inquiry, however, this sample consisted primarily of young, single, female college students. This sample's knowledge, attitudes, social norms, intentions, and potential behaviors may not

reflect the full range found in the general public. Further, participants were not recruited based on genetic status or relationships with indivdiuals having genetic or genetic-linked disorders. Personal experience with genetic and genetic-linked disorders, especially mental (i.e., Schizophrenia, Bipolar, etc.) and cognitive disorders (i.e., Down's syndrome, Angelman syndrome, Autism, etc.) may have exerted a greater influence on participant attitudes than noted.

Even so, the researcher has attempted to perserve participants' voices as much as possible. Transcripts were analyzed by responses to separate questions rather than aggregated, to perserve, when possible, the richness and context in which participants made their responses. In addition, the researcher attempted to establish correspondence and coherence of the data by presenting direct quotes from study participants and mirroring participants' language in interpreting study findings. Whether these study findings are persuasive in describing how perception of genetic risk influences sexual and reproductive decision-making is the subject of future inquiry.

Implications for Practice

With the completion of the Human Genome Project, the general public faces an increasing amount of highly technical information. Laypersons must have the basic knowledge, skills, and attitudes to critically evaluate their own risk and access appropriate genetic-based technology and services. Understanding how laypersons interpret and communicate about complex concepts such as genetic risk and inheritance are vital to helping health professionals to change or to develop programs that increase

awareness and educate the public (Johnson et al., 2001; Johnson et al., 2005; U.S. Department of Health and Human Services, 2000). Furthermore, understanding how this information is used in real life may prove vital to assisting the public with making fully informed reproductive and sexual health decisions. In order to do so, health professionals must understand the psychosocial and environmental variables that guide these decisions, as well as any potential benefits and perception of barriers.

As this study demonstrates, qualitative methodologies lend themselves well to illuminating subjective experiences, meanings, and motivations. These methodologies are particularly useful for determining how groups think and why they behave in specific ways. Further qualitative research needs to be performed to understand the positive and negative impact that participation in a collective consciousness (e.g., social norming agents such as family, friends, or church members) might have on sensitive decisions such as those involved in sexual and reproductive health. Health professionals need to have an understanding of the group dynamic in order to counter decisions based on misinformation or poor health literacy. Studies that qualitatively examine emerging theory or existing ones such as the *Health Belief Model, Theory of Reasoned Action, Theory of Planned Behavior, Gaming Theory, The Transactional Model of Stress and Coping,* or *Neuroeconomics Theory*, might yield a deeper, richer understanding of this form of decision-making.

CHAPTER IV

QUANTITATIVE PHASE DATA OF THE PERCEPTION OF GENETIC RISK IN SEXUAL AND REPRODUCTIVE DECISION-MAKING (PGRID) BY COLLEGE STUDENTS STUDY

Introduction

The Perception of Genetic Risk in Sexual and Reproductive Decision-making (PGRID) by College Students Study is a quantitative study that is part of a larger multi-site, mixed methods research project. This mixed-methods project intends to address the question "how does perception of genetic risk influence sexual and reproductive intention by college students?" The specific aims of the quantitative study reported herein are to answer the following questions. For a sample (N=2,576) of young adult college students in the Southwestern U.S.: 1) What psychosocial factors influence genetic risk perceptions and specific sexual/reproductive intentions (i.e., intentions to date, marry and have children with individuals who are carriers or affected by a genetic disorder)? and 2) Which theory-based variables predict sexual and reproductive intention; specifically, intention to date, marry, and have children with individuals who are carriers or affected by a genetic disorder?

Theoretical Framework

Theory provides a way of describing, explaining, or predicting a variety of phenomena (Glanz, Rimer, & Lewis, 2002, pp. 25-26). Multiple evaluations have

demonstrated that theory-based interventions have a higher likelihood of yielding relevant outcomes than interventions that lack a theoretical framework (Glanz et al., 2002; Goodson, Pruitt, Suther, Wilson, & Buhi, 2006b). Likewise, theory-based health behavior research contains a built-in *systematic* method for identifying behavioral *antecedents*; proximal and distal mechanisms which affect these antecedents; and their subsequent influence on behavior (Goodson et al., 2006b).

Yet, theories vary based on their initial *assumptions* and *hypotheses* (Glanz et al., 2002; Goodson et al., 2006b). They also vary in their "degree of specification, comprehensiveness, parsimony, empirical support, and ease of translation into health promotion intervention strategies" (Fisher & Fisher, 1998, p. 40). Prior to designing research or practice interventions, one should conduct a thorough examination of relevant theories. Theories appropriate to the goal of the intervention, the socio-environmental context, and the population of interest should be considered for inclusion in a study or programmed intervention (Glanz et al., 2002).

Evolutionary Psychology

Despite the emergence of evolutionary theory in the mid-19th century, Evolutionary Psychology (EP) did not appear as a distinct school of thought until the 1980s (Buss, 2000). Its emergence represented the first time that evolutionary theory was *systematically* infused with psychological theory (Corballis & Lea, 1999). Evolutionary Psychology is primarily concerned with issues related to adaptation

(Allegeier & Wiederman, 1994). These issues may be broadly categorized into mating tactics and preferences among humans (i.e., sexual attractiveness cues).

Evolutionary psychologists hypothesize that certain psychological mechanisms were adaptive for early humans, as those who possessed these traits were more likely to survive and reproduce than those who did not possess them (Allegeier & Wiederman, 1994). These adaptations were *context-specific* and the product of biological and environmental interaction, not *biological determinism* (Allegeier & Wiederman, 1994; Buss, 2000). Rather, males and females differed in terms of mate selection preferences due to differential requirements in *reproductive potential* and *parental investment* (Allegeier & Wiederman, 1994; Geary et al., 2004; Sterelny & Fitness, 2003; Woodward & Richards, 2004).

Based on the EP perspective, sexual attractiveness cues utilized in mate selection vary across a range of physical, emotional and personality domains. In one review, Miller (1997) lists "height, intelligence, walking speed, facial symmetry, sense of humor, waist-to-hip ratio, degree of genetic relatedness…political status, and sexual foreplay skills" as adaptive sexual attractiveness cues (p. 71). Other commonly described cues include body odor (major histocompatibility complex genotype), sexual fantasies, and social and financial resources. Human mate selection preferences are described at length, from an EP theoretical point-of-view, in a number of book chapters, articles, and reviews (see Allegeier & Wiederman, 1994; Buss, 2000; Dunbar & Barrett, 2007; Gangestad & Simpson, 2007; Geary et al., 2004; Miller, 1997; Sterelny & Fitness, 2003).

Social Cognitive and Behavioral Theories

While EP research provides a vast array of empirical research on sexual attractiveness cues and tactics, many evolutionary psychologists including Miller (1997) argue that "mate choice (research) may get stuck…producing an ever-expanding catalogue of cues demonstrated to have a statistically significant effect on attractiveness judgments in laboratory experiments, but never progressing to detailed (*context-sensitive*), testable models" (p. 72). Rather than focusing on individual biological processes, social cognitive and behavioral (SCB) theories add (to EP theories) the social and cognitive dimensions of behavior, as well as degrees of behavioral intention and control, to the understanding of mate selection. Commonly known theories within this category include the Health Belief Model (HBM) and the Theory of Planned Behavior (TPB). These theories are also commonly employed in empirical studies exploring genetic risk and sexual and reproductive health decisions (Gooding, Organista, Burack, & Bowles Biesecker, 2006; Katapodi, Lee, Facione, & Dodd, 2004; Wang, Charron-Prochownik, Sereika, Siminerio, & Kim, 2006).

Figure 1 represents the conceptual underpinning for the current study. This model, which combines HBM and TPB factors, may contribute constructs that facilitate understanding of the potential relationship between genetic risk perception and sexual and reproductive decision-making. Constructs including *perceived risk* (or perception of risk), *perceived severity, perceived benefits*, and *perceived barriers* originate from the HBM. The TPB provides constructs including *perceived behavioral control* (or *self-*

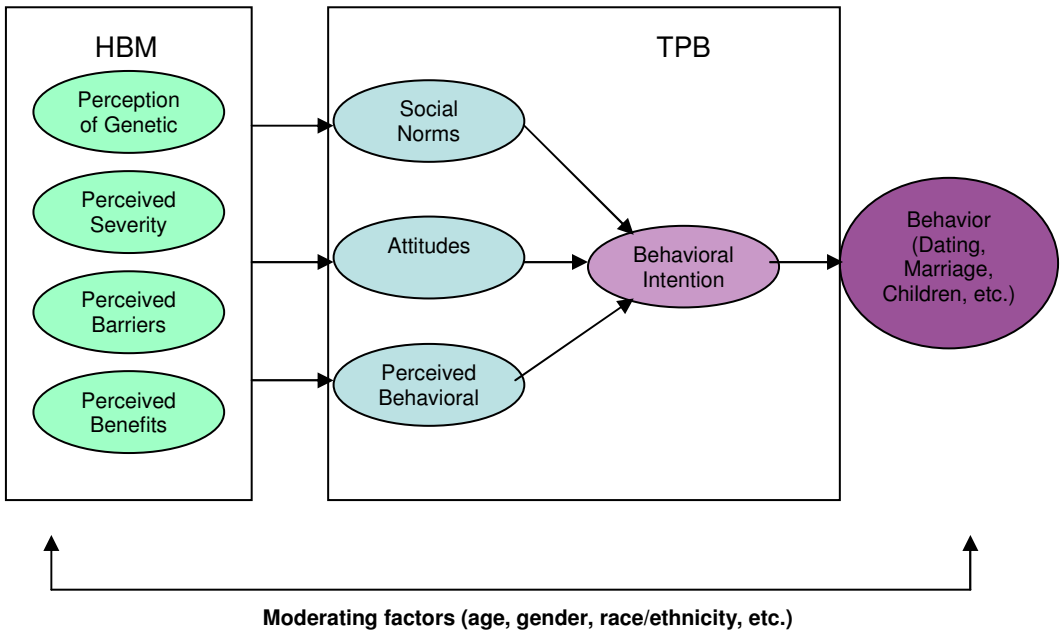

Figure 1. Emerging Theory from Qualitative Inquiry and Existing Theoretical Constructs

efficacy), *subjective norms*, (intra-personal) *attitudes* and *behavioral intention*. Data for evolutionary psychology variables were collected for inclusion in a future study

Young adults who feel that they are at risk for developing a genetic/genomic disorder (perception of risk) may assess the potential consequences (perceived severity) of inheriting, developing or "passing on" the disorder, for themselves and/or for their partners, families, or children (current and/or future). These young adults may also assess potential benefits and barriers to reproductive decision-making, which may include steps taken towards preparation, prevention, or treatment of the genetic disorder. Adding in TPB constructs, a young adult's attitude towards a particular genetic/genomic disorder (or its consequences), confidence in his/her ability to exercise some degree of control (perceived behavioral control) over inheriting, developing or "passing on" the disorder, and his/her prevailing social norms may influence sexual and reproductive intention and, thus, decision-making.

Based on the proposed model, TPB variables may mediate the relationship between HBM constructs and intention. TPB factors will also serve as predictors of behavioral intention. Factors that may exert a moderating influence on this relationship include individual factors (e.g., carrier status, personality) and demographic variables (e.g., age, race/ethnicity, religion).

Method

Sample and Setting

The population for this study was college-aged (undergraduate and graduate) adults, ages 18 years or older, in a Southwestern U.S. state. As of July 2006, the *American Community Survey* indicated that 8.7% of that state's population (about 1.5 million individuals), age 18 years or older, were currently "enrolled in college or graduate school" (U.S. Census Bureau, 2007). This number was almost evenly divided between males and females.

The sampling frame for this study represented all currently enrolled students who were 18 years or older during the 2007-2008 academic year (i.e., the only inclusion criteria for participation), at two state universities (sites), who had not opted out of their campus information directories. Site one served a majority of Caucasian students with substantial minority and international student enrollment (approximately 42,000 students). This site was located in a rural county. Site 2 was a majority Hispanic student-serving instiution located in a major metropolitan area (approximately 26,000 students). Sites were selected because of existing professional relationships with university faculty and familiarity with university administration. Each site provided Institutional Review Board approval to perform the study.

Sample size represents a critical element in calculating study power and effect sizes. In lieu of power analysis, this research study utilized Dillman's (2007) method for estimating sample size. To obtain statistical representation (limiting sampling error to

±5%), the appropriate sample size for a 95% level of confidence for a total population of 68,125 students was 382 students (Dillman, 2007).

Instrument (Construct Validity and Reliability)

Results from a systematic review of the literature, as well as findings from the qualitative portion of the mixed-methods study (reported in Chapter III) were used to develop a quantitative, web-based survey. This survey used 138 closed-ended questions, not including demographics, to assess attitudes, intentions, social norms, perceptions, and perceived behavioral control related to perception of genetic risk and sexual and reproductive decision-making (see Figure 1). Items were ordinally or intervally scaled. Scales (and subscales) corresponding to Health Belief Model factors (i.e., perceived risk, perceived severity, perceived barriers, and perceived benefits) and Theory of Planned Behavior (TPB) variables (i.e., social norms, attitudes, perceived behavioral control, and intentions) were created by summing related items.

An initial draft of the instrument was sent to a panel of four experts in the fields of health education and genetic counseling for assessment of content validity (i.e., did the instrument address the scope and nuances of the variables of interest; See Figure 2). Their commentary was used to revise the instrument. After this revision, the researcher performed cognitive interviews with three students who were not classified as biology or genetics majors (see Dillman, 2007 for further information on cognitive interviewing). The instrument underwent further revision based on the results of cognitive interviewing (see Figure 2).

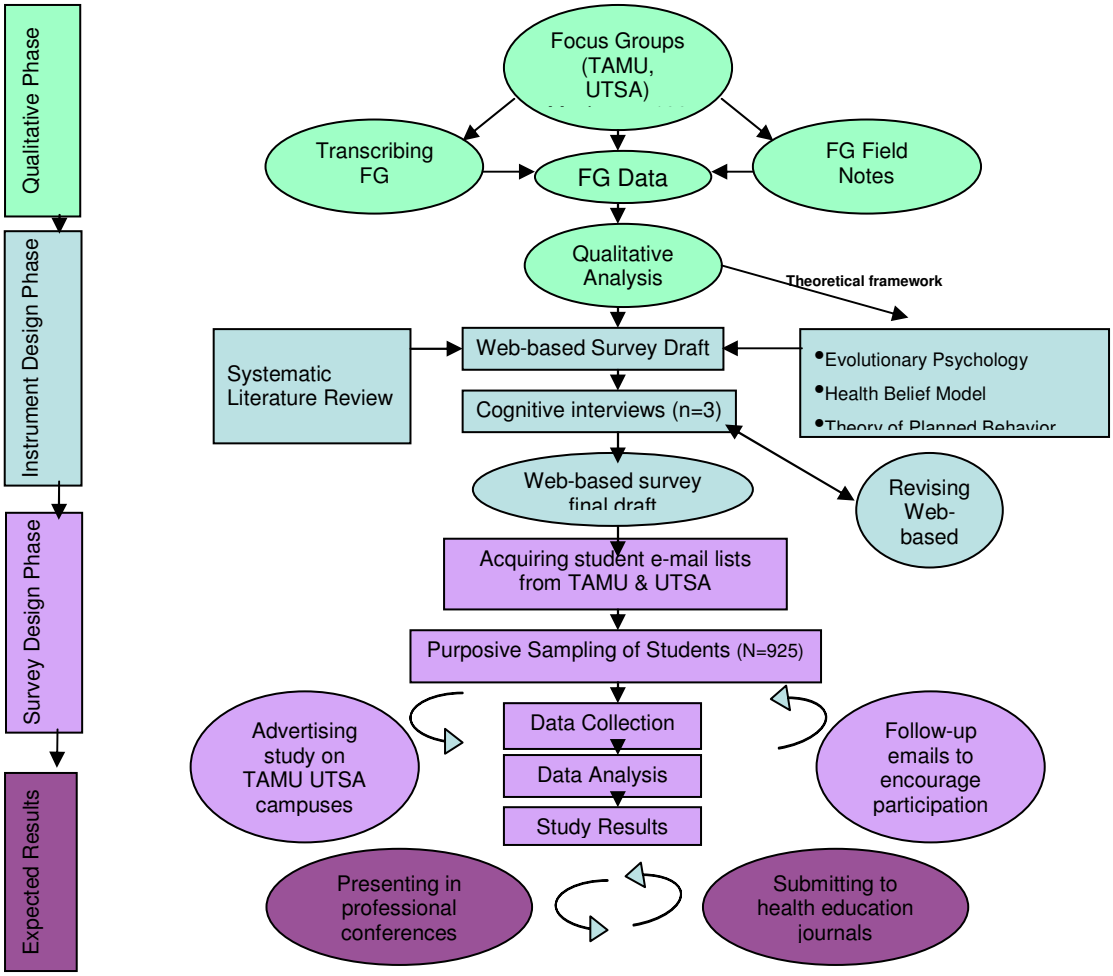

Figure 2. Mixed Methods Study Design

After data collection, the instrument and subscales were analyzed for reliability (internal consistency) and construct validity using SPSS 15.0. Internal consistency was assessed using Cronbach's alphas. Construct validity was established using principal axis factor analysis with varimax rotation. Results of these analyses by scale and subscales are presented below. Higher item and scale/subscale scores correspond to stronger agreement with the item's stem, except where noted.

Variables Measured

- *Sexual and reproductive intentions*: Specifically, the instrument measures students' *intentions to date, marry, or have children with* an individual who 1) "does not know his/her genetic status (genotype)," 2) "is an asymptomatic carrier (i.e., has the genes, but will not develop symptoms) for a specific disorder," 3) "is a symptomatic carrier (i.e., has the genes, and also has symptoms) for a specific disorder," 4) "has a physical disability that is genetic in origin," 5) "has a mental disorder that is genetic in origin," and 6) "has any type of genetic disorder." College students were asked to repond to questions containing these six scenarios, for each of three intention variables (an example of one of these questions would be, "how likely are you to *date* someone who is a symptomatic carrier for a specific disorder?"), using a 5-point Likert scale ranging from "Not at all likely (Never)" to "Extremely likely (Always)." Items were summed to create a subscale for each factor. Higher scores correspond to stronger intention. Reliability

analysis of data on these 18 items resulted in a Cronbach's α of .952 (scale M=31.65, SD=13.35).

A Principal Components Factor Analysis with Varimax rotation was employed to gauge whether the items (designed specifically for this study) actually measured the intended constructs.

- *Dating intention*. For dating intention, two factors resulted from the Varimax rotation procedure. Dating intention factor 1 accounted for 39.03% of the item variance (i.e., dating intention with unknown status and dating intention with asymptomatic carrier) and factor 2 (e.g., dating intention with symptomatic carrier, physical disability that is genetic in origin) accounted for 29.27% of item variance. Cronbach's α for the dating intention variable was .875 (M=11.9, SD=4.51).
- *Marital Intention*. All of the items measuring intention to marry, converged on a single factor. This factor explained 61% of the sub-scale's variance. Cronbach's α for the marital intention variable was .898 (M=10.7, SD=4.91).
- *Childbearing intention*. Items assessing childbearing intention were associated with a single factor. This factor explained 65.33% of item variance. Cronbach's α for the childbearing intention variable was .910 (M=9.01, SD=5.14).

- *Social norms*: *Social norms* were assessed within six dimensions, i.e., family dating norms, family marital norms, family childbearing norms, friend dating norms, friend marital norms, and friend childbearing norms. College students were asked to repond to six questions, each representing a different scenario, per social norm, using a 4-point Likert scale ranging from "Strongly disagree (Would disapprove outright)" to "Strongly agree (Would approve unconditionally)." Sample items included: "If I dated someone who has any type of genetic disorder, my family would…" and "If I dated someone who has a physical disability that is genetic in origin, my friends would…" Items were summed to create a subscale for each factor. Higher scores correspond to stronger social approval. Reliability analysis for data on these 36 items resulted in a Cronbach's α of .979 (scale M=59.95, SD=22.41). Cronbach's α for family dating norms (M=10.51, SD=4.07), family marital norms (M=10.14, SD=4.3), family childbearing norms (M=9.34, SD=4.51), friend dating norms (M=10.51, SD=3.78), friend marital norms (M=10.14, SD=4.05), and friend childbearing norms (M=9.31, SD=4.33) variables were .920, .932, .937, .907, .920, and .927, respectively. The factor analysis extracted one factor per social norm and explained 63.23%-72.12% of each social norm sub-scale.

- *Perceived behavioral control (PCB)*: Similar to the 'intentions' variables *perceived behavioral control* (PBC) was assessed for the three behaviors: dating, marrying, and childbearing. College students were asked to repond to five

scenarios per PBC variable (e.g., "I have control over whether I date someone who is an asymptomatic carrier"), using an 11-point Likert scale ranging from "0% (No control)" to "100% (Complete Control)." Items were summed to create a subscale for each factor. Higher scores correspond to stronger perceived control. Reliability analysis for data on these 15 items resulted in a Cronbach's α of .948 (scale M=108.16, SD=35.28). Cronbach's α for dating PBC (M=32.66, SD=13.72), marital PBC (M=36.71, SD=13.13), and childbearing PBC (M=38.79, SD=12.91) variables were .903, .909, and .919, respectively. Factor analysis extracted one factor per behavior (e.g., one for dating PCB, one for marrying PBC, and one for childbearing PBC) and explained between 66.89% and 72.93% of each sub-scale's variance.

- *Attitudes*: *Attitudes* were assessed for six dimensions: dating values, marital values, childbearing values, dating beliefs, marital beliefs, and childbearing beliefs) related to sexual and reproductive decision-making within the genetic status scenarios. College students were asked to repond to six questions per attitude dimension, scaled on a 4-point Likert scale ranging from "Strongly disagree" to "Strongly agree" for beliefs and "Not important at all" to "Extremely important" for values. Sample items included: "It is okay for individuals who have any type of genetic disorder to date." (belief) and "I believe that it is _____ if the person I am dating (or will date) has any type of genetic disorder" (value). Items were summed to create a subscale for each factor. Higher scores

correspond to stronger values or beliefs. Reliability analysis for data on these 36 items resulted in a Cronbach's α of .861 (scale M=92.82, SD=12.60). Cronbach's α for dating beliefs (M=20.98, SD=3.65), marital beliefs (M=20.19, SD=4.10), childbearing beliefs (M=16.82, SD=5.16), dating values (M=9.54, SD=4.35), marital values (M=11.58, SD=4.56), and childbearing values (M=13.71, SD=4.60) were .955, .950, .938, .909, .929, and .943, respectively. One factor was extracted per attitude dimension, explaining between 63.71% and 77.14% of the subscales' variance.

- *Perceived severity*: Participants' *perceived severity* of specific genetic, genetic-linked, and non-genetic disorders was assessed using nine items, scaled on a 10-point Likert format, from "Not severe at all" to "Extremely severe." Here, a higher score corresponds to higher perceived severity of the disorder. Items were presented in a matrix format with a stem reading "Please rate the severity (seriousness) of each of the following conditions." Items being rated included bipolar disorder, cervical cancer, depression, Down's syndrome, genetic disorders in general, HIV/AIDS, physical disabilities, schizophrenia, and sickle cell anemia. Reliability analysis for data on these 9 items resulted in a Cronbach's α of .834 (scale M=70.03, SD=11.35). Only one factor was extracted for this variable accounting for 36.57% of the scale's total variance.

- *Perceived risk*: Participants' *perceived risk* of specific genetic, genetic-linked, and non-genetic disorders was assessed using nine items, scaled on a 11-point Likert format, from "0% (No risk)" to "100% risk." Items were presented in a matrix format with a stem reading "Please rate your risk (susceptibility) for developing each of the following conditions." Here, a higher score corresponds to higher perceived risk for developing the disorder. Items being rated included bipolar disorder, cervical cancer, depression, Down's syndrome, genetic disorders in general, HIV/AIDS, physical disabilities, schizophrenia, and sickle cell anemia. Reliability analysis for data on these 9 items resulted in a Cronbach's α of .902 (scale M=21.86, SD=17.96). Only one factor was extracted for this variable accounting for 54.05% of the variance.

- *Perceived Barriers*: Participants' *perceived barriers* to "having healthy children" was assessed using eight items, scaled on a 4-point Likert format, from "Not a barrier at all" to "A strong barrier." Here, higher scores are associated with perceiving specific items as stronger obstacles to bearing healthy children. Sample items included: "lack of knowledge about genetics" and "mistrust of genetic technology and services." Reliability analysis for data on these 8 items resulted in a Cronbach's α of .882 (scale M=12.98, SD=5.39). For perceived barriers, two factors resulted from the Varimax rotation. Factor 1 accounted for 35.71% of the scale's variance (e.g., lack of knowledge about genetics, lack of financial resources) and factor 2 (i.e., incompatability between family planning

and religious beliefs, and lack of knowledge about one's own, or a partner's, family tree) accounted for 27.07% of the variance. Together, the two factors explained 62.78% of the variance.

- *Perceived Benefits*: Participants' *perceived benefits* of "having healthy children" was assessed using seven items, scaled on a 4-point Likert format, from "Not a benefit at all" to "A strong benefit." Sample items included: "having a 'healthy' child" and "having a child who has a better quality of life." Higher scores correspond to stronger benefits. Reliability analysis for data on these 7 items resulted in a Cronbach's α of .853 (scale M=17.30, SD=3.89). For perceived benefits, two factors resulted from the Varimax rotation. Factor 1 accounted for 34.44% of the variance (e.g., "having a 'healthy' child," "having a child who has a better quality of life") and factor 2 (e.g., "having no feelings of guilt about 'passing on' a genetic disorder or defect") accounted for 29.79% of the variance. Together, the 2 factors explained 64.23% of the variance.

Reliability analysis for data on this 138-item instrument resulted in a cronbach's α of .889 (M=414.74, SD=52.21). In addition to the instrument, the survey contained items that were measured, but not portrayed in the conceptual model. Analyses of these items, along with descriptions of how they were measured, are presented in the Results section.

Data Collection

All eligible members of the sampling frame (Site 1, n=42,411; Site 2, n=25,714) who had not opted out of their campus directories received an introductory e-mail containing a personalized link to the web-based survey. Participants who opened the link were taken directly to an information sheet. This sheet contained information on the nature and purpose of the study, its objectives, procedures, anticipated risks and benefits, participant compensation, and study personnel's contact information, as well as contact information for each school's Institutional Review Board, student health center, and counseling center. Students who agreed to participate in the study were taken to the survey, which took an estimated 20 minutes to complete. After completing the survey, they were offered the opportunity to participate in a random drawing for incentives worth approximately $5-25 each (i.e., gift cards and movie tickets) via a link to a separate web page that allowed them to enter their contact information. Students who had not completed the survey or "opted out" of the study were sent a reminder via e-mail one week later.

Data were collected for this study using Zoomerang™, an online survey service, which supports web-based survey development, data collection, and data analysis. The Zoomerang zPro tool represented a more efficient, cost-effective, and confidential means of collecting web-based survey data. The survey remained available for two weeks. After the survey cut-off date, the data were downloaded and analyzed using SPSS® 15.0.

Data Analysis

SPSS® 15.0 was used to perform descriptive and univariate analyses, as well as factor analysis and calculation of the Cronbach's alpha (measure of internal consistency) for instrument scales/subscales. Listwise deletion of cases with missing values was employed to standardize sample sizes for scales/subscales, resulting in a loss of 2.17% of 2,576 cases (n=56). Descriptive analyses were used to assess frequencies of responses to questions and normality (univariate) of the data distribution. All of the data were univariate non-normal (e.g., 45 items had skewness values between 1 and 2, six items had values between 2 and 4), therefore univariate analyses were performed using non-parametric analyses including Mann-Whitney U and Kruskal-Wallis tests (i.e., alternatives to *t*-tests and ANOVAs, which are not as robust to violation of the normality assumption).

Multiple regression analysis (with the use of SPSS® 15.0) was utilized to statistically examine variables influencing sexual and reproductive intention (i.e., dating, marital, and childbearing intention) towards individuals who are carriers or affected by a genetic disorder. Potential predictor variables were selected from the scientific literature, existing theory, and themes emerging from the qualitative phase of the larger, mixed-methods study (See Figure 1). Regression models tested and modeled relationships between a set of these predictors (e.g., genetic risk perceptions, age, race/ethnic heritage, perceived barriers) and the outcome variable, intention (i.e., dating, marital, or childbearing). Results, presented below, were organized by research question.

Results

Demographics

Over 2,500 students (N=2,576) completed the web-based survey (Site 1, n=1,648, response rate=3.89%; Site 2, n=928, response rate=3.61%). Survey respondents were primarily single, young, and female. Females represented about two thirds (64.8%) of all students who completed the survey. While participants ranged in age from 18 to 72 years (n=2,520), they were, on average, 23.4 years of age (SD=6.6 years). Most participants (94.3%) were less than 35 years old.

Respondents varied in terms of marital and parenting status (i.e., had biological children). Over three quarters of participants were un-married (85.4%, n=2,152). Un-married participants were single, not dating (30.4%), in long-term dating relationships (25.5%), or single and dating (16.0%). Fewer un-married participants were in cohabitating (4.8%), engaged (4.5%), or short-term dating relationships (4.2%). Non-single status participants included those who were married (12.8%), divorced (1.5%), married, but separated (0.3%), and widowed (n=1).

A number of respondents had biological children (10.2%). Of this number, almost three quarters (74.4%) were married. The remaining parents were unmarried including those who were single, and not dating (4.4%), short-term dating (4.4%), and long-term dating (16.7%).

Respondents also varied in terms of racial/ethnic heritage, annual household income, religious/spiritual preference, and religiosity. Respondents who identified their racial or ethnic heritage as “White or Caucasian” (66.3%) represented the largest group.

The remaining participants were “Hispanic or Latino” (19.3), “Asian” (6.4%), “Other” (4.6%), “Black or African American” (3%), “Native Hawaiian or Pacific Islander” (0.3%), or “American Indian or Alaska Native” (0.2%). Participants who selected “Other” included those of biracial or multi-racial ancestry, as well as those who represented multiple ethnic groups (e.g., German, Italian, Creole).

Students were then asked to select the range that best described their (or their parents’) annual household income. To increase accuracy, graduate students or those who were financially “independent” were asked to select the range that best described their annual household income. A number of participants reported annual incomes of “greater than $100,000” per year (28.1%). However, the majority of participants’ income was between $0 and $74,999 per year (57.9%).

Participants also varied in terms of their religious or spiritual preference. Students reporting “Other” religious or spiritual preference (52.1%) represented the largest group. This figure included a number of participants better classified as “Protestant.” (Only one person selected “Protestant” as a response option.) In addition to individuals from various Protestant denominations (e.g., Baptist, Methodist, Lutheran, Seventh Day Adventist, Unitarian Universalist), the “Other” category included individuals who were “Deists,” “Baha’i,” “born again Christian,” “non-denominational Christian,” “Eastern Orthodox,” “Greek Orthodox,” “Humanist,” “spiritual,” “Wicca,” “Sikhi,” or “Zorastrianist.”

Participants also varied in terms of religiosity and frequency of religious or spiritual service attendance. A number of participants considered themselves “slightly”

(25.7%) or "moderately" (40%) religious or spiritual and attended services zero (46.3%) or one time (36.4%) per week. Less than one quarter of participants described themselves as "very religious or spiritual" or attended a service more than five times per week (1.7%).

Exposure to Formal Genetics Education and Family History Tools

Respondents who reported their current educational status (n=2514) were undergraduate (79.3%) or graduate (20.1%) students. However, a small number were professional (0.6%, i.e., medical, law) students. Over three quarters (81.1%) of students who completed the survey were enrolled in a degree programs other than biology, genetics, or related fields of study.

Participants were asked whether they had "ever taken a genetics course." Of those currently pursuing a biology, genetics, or related degree, over one half (54.9%, n=261) had ever taken a genetics course compared to 9.1% (n=186) of non-majors. Participants were then asked whether they had "ever charted (their) family tree (genealogy)" or "family health history." Respondents who had charted their family were almost evenly divided between major and non-majors (48.2% vs. 49.4%), with non-majors charting their family tree at higher rates.

Genetic Information Sources

Respondents were asked to describe how often they used media to obtain genetic information (modified from the *2004 General Social Survey*). Questions contained a 5-

point Likert scale (0="Never," 4="Very Often"). Based on survey responses, television (M=1.92, SD=1.04) and internet (M=1.40, SD=1.12) represented the two highest ranked media sources. Participants watching television "often" (25.8%) or "very often" (5.5%) received genetic information through television programming. Internet users reported "often" (15.1%) or "very often" (3.7%) receiving genetic information through this source. On average, radio (M=0.93, SD=0.97) and newspapers (M=0.96, SD=0.93) were "not very often" used as genetic information sources.

Respondents were also asked to describe how often they discuss genetics with different types of individuals. Overall, participants did not often talk about genetics. However, if they did speak with someone to obtain genetics information, they primarily reported talking to relatives (M=1.62, SD=1.10) or friends (M=1.54, SD=1.07). A number of respondents reported speaking with relatives or friends "often" (18.1% vs. 15.2%) or "very often" (4.0% vs. 3.9%) about genetics. In contrast, they did "not very often" speak with physicians (M=1.13, SD=0.97) or genetic specialists (e.g., genetic counselors, geneticists) for information (M=0.69, SD=0.97).

Attitudes and Experiences with Genetic Technology

The last part of the demographic section of the web-based survey assessed general attitudes and experiences with genetic technology. When asked to assess how much they have "read or heard about genetic testing," a number of respondents reported "nothing at all" (8.6%) or "not very much" (72.3%). Fewer reported that they had read or heard "a great deal" (13.1%) about genetic testing or "I don't know" (5.8%).

Respondents were then asked, “Based on what you know, do you think that genetic screening will do more good than harm, or more harm than good?” Responses varied; however, more participants expressed views that genetic screening would do “more good than harm” (41.4%) or “it depends” (38.4%). Fewer respondents reported that genetic screening would do “more harm than good” (7.6%). A related question asked participants “if you or your partner were pregnant, would you want (her)” to undergo prenatal testing “to determine if the baby has any serious genetic disorders?” Of those who responded to the question, a majority of participants (57.7%) reported that they would use prenatal testing; however, a number of participants would forego prenatal testing (21.4%) or were undecided (19.9%).

While the previous questions assessed attitudes towards genetic technology, the following questions assessed respondents’ experiences with genetic technology. Participants were asked, “Have you ever had genetic testing to determine if you carry a specific gene(s) for a specific genetic disorder(s)?” Less than 10% of respondents reported they had ever undergone genetic testing (6.3%); some participants were uncertain if they had ever been tested (4.2%). A higher number of respondents (30.7%) reported that they underwent prenatal testing genetic disorders during pregnancy.

Dating, Marital, and Childbearing Intentions

Several scenarios were created to assess participants’ intentions to date, marry, or have children. These scenarios included, as the object of the three behaviors, individuals of unknown genetic status, asymptomatic carriers, symptomatic carriers, as well as

indviduals having physical disabilites or mental disorders that are genetic in origin, or any type of genetic disorder. Participants varied a great deal in their responses concerning dating, marital, and childbearing intentions; however, a few trends emerged from this data.

On average, respondents expressed that they were "very likely" or "extremely likely (always)" to date individuals of unknown genetic status (70.5%, n=1,778) or asymptomatic carriers (49.6%, n=1,250). Fewer reported that they were "very/extremely likely" to date individuals having *any* genetic disorder (22.4%, n=565), were symptomatic carriers (21.8%, n=549), or those having physical disabilities (16.2%, n=408) or mental disorders (8.6%, n=216) that are genetic in origin. A number of respondents indicated that they were "not at all likely (never)" or "not very likely" to consider dating someone who had any type of genetic disorder (29.4%, n=742), were symptomatic carriers (38.3%, n=965), or had physical disabilities (48.2%, n=1,214) or mental disorders (70.7%, n=1,782) that are genetic in origin. In contrast, fewer respondents reported that they were "not at all/not very likely" to marry an individual of unknown status or an asymptomatic carrier, 7.0% (n=176) and 12.9% (n=324), respectively.

Fewer respondents indicated that they were "very/extremely likely" to marry individuals of unknown genetic status (55.5%, n=1,400) or asymptomatic carriers (40%, n=1,008). This trend also applied to those who were "very/extremely likely" to marry individuals who are symptomatic carriers (18.4%, n=464); have any type of genetic disorder (17.1%, n=432) or individuals having physical disabilities (13.4%, n=337) or

mental disorders (8.4%, n=212) that are genetic in origin. An increasing number of respondents indicated that they were "not at all/not very likely" to marry someone who has any type of genetic disorder (41.2%, n=1,386), symptomatic carriers (45.8%, n=1,496), or individuals having physical disabilities (57%, n=1,686) or mental disorders (71.7%, n=1,915) that are genetic in origin. Fewer reported that they were "not at all /not very likely" to marry an individual of unknown genetic status or an asymptomatic carrier, 15.6% (n=681) and 20.7% (n=893), respectively.

While participants expressed that they were "likely/extremely likely" to have children with individuals of unknown genetic status (41.7%, n=1,052) or asymptomatic carriers (26.2%, n=659). Fewer would do so with individuals who are symptomatic carriers (18.4%, n=296); have *any* type of genetic disorder (17.1%, n=296); or individuals having physical disabilities (13.4%, n=229) or mental disorders (8.4%, n=156) that are genetic in origin. The highest frequency of "not at all/not very likely" responses were related to childbearing intentions with individuals with any type of genetic disorder (55%), symptomatic carriers (59.4%), and individuals having physical disabilities (66.9%) or mental disorders (76.0%) that are genetic in origin.

Univariate and Multivariate Analyses

Non-parametric univariate (i.e., Mann Whitney U and Kruskal-Wallis tests) and multivariate (i.e., multiple regression) analyses were performed to answer the research questions. Presentation of results is organized, below, by research question.

Question 1: "What psychosocial factors influence genetic risk perceptions and intentions to date, marry or have children with individuals who are carriers or are affected by a genetic disorder?"

Gender

Gender moderated perceptions of genetic risk, among this sample (see Table 9). On average, females' perceived risk (susceptibility) for developing specific genetic and genetic-linked disorders was higher (Mean rank=1306.58) than that of their male counterparts (Mean rank=1175.82). This difference in perception was statistically significant (z=-4.311, p=.000). There were no significant differences between males and females concerning dating (z=-1.854, p>.05), marital (z=-0.641, p>.05), or childbearing (z=-1.403, p>.05) intentions.

Race/Ethnic Heritage

Race and ethnic heritage also moderated perceptions of genetic risk in our sample (see Table 9). The "Other" group's perceived risk for developing specific genetic and genetic-linked disorders was, on average, higher (Mean rank=1345.98) than that of their Hispanic/Latino (Mean rank=1319.01) or White/Caucasian counterparts (Mean rank=1224.99). White/Caucasians had, on average, significantly lower risk perceptions than either Hispanic/Latinos (z=-2.54, p=.011) or Others (z=-2.832, p=.005). The differences in genetic risk perceptions were not differ significantly between Hispanic/Latinos and Others.

Table 9. Mann Whitney U and Kruskal-Wallis

Predictor	DV	Mann Whitney U	MWU Mean rank	Kruskal-Wallis	KW Mean rank (with Mann Whitney comparison)	z-approximation test	p-value
Gender	perception of genetic risk	649409.5	female=1306.58 male=1175.82	N/A	N/A	z=-4.311	p=.000
	dating intention	692354	female=1280.26 male=1224.18	N/A	N/A	z=-1.854	p>.05
	marital intention	713450.5	female=1267.34 male=1247.94	N/A	N/A	z=-0.641	p>.05
	childbearing intention	700190	female=1245.54 male=1288.00	N/A	N/A	z=-1.403	p>.05
Racial/ethnic heritage	perception of genetic risk	375597 273950 85704.5	White/Caucasian=1224.99 Hispanic/Latino=1319.01 Other=1345.98	$c^2(2)=12.131$, p=.002	(W,H)=(1064.14, 1142.67) (W,O)=(1000.35, 1096.73) (H,O)=(419.85, 430.75)	z=-2.540 (W&H) z=-2.832 (W&O) z=-0.641 (H&O)	p=.011 p=.005 p>.05
	dating intention	333076.5 225434.5 79059.5	White/Caucasian=1346.6 Hispanic/Latino=1141.47 Other=1022.64	c2(2)=75.549, p=.000	(W,H)=(1119.42, 942.15) (W,O)=(1063.67, 804.25) (H,O)=(442, 399.9)	z=-5.538 (W&H) z=-7.642 (W&O) z=-2.532 (W&O)	p=.000 p=.000 p=.011
	marital intention	355208.5 238105.5 79733	White/Caucasian=1329.65 Hispanic/Latino=1172.32 Other=1059.51	c2(2)=50.13, p=.000	(W,H)=(1110.05, 974.38) (W,O)=(1056.09, 839.25) (H,O)=(441.44, 401.76)	z=-4.237 (W&H) z=-6.386 (W&O) z=-2.340 (W&O)	p=.000 p=.000 p=.019

Table 9. Continued

Predictor	DV	Mann Whitney U	MWU Mean rank	Kruskal-Wallis	KW Mean rank (with Mann Whitney comparison)	z-approximation test	p-value
Marital status	childbearing intention	N/A	Single, Not Dating=1227.54 Short-term Dating=1271.61 Long-term Dating=1227.61 Married=1264.39	$c^2(3)$ =5.770	N/A	N/A	p>.05
Religious/ Spiritual Preference	perception of genetic risk	N/A	Catholicism=1293.56 Protestantism=1235.04 Other=1251.07	$c^2(2)$ =1.836	N/A	N/A	p>.05
	dating intention	N/A	Catholicism=1202.62 Protestantism=1271.19 Other=1280.98	$c^2(2)$ =5.424	N/A	N/A	p>.05
	marital intention	N/A	Catholicism=1232.10 Protestantism=1309.24 Other=1265.45	$c^2(2)$ =1.943	N/A	N/A	p>.05
	childbearing intention	N/A	Catholicism=1292.68 Protestantism=1356.72 Other=1237.13	$c^2(2)$ =6.477, p=.039	(C,P)=(411.38, 432.89) (C,O)=(1198.79, 1147.49) (P,O)=(1023.33, 934.14)	z=-1.102 (C&P) z=-1.647 (C&O) z=-2.186 (P&O)	p>.05 p>.05 p=.029
Annual Income	perception of genetic risk	23924 50138 23255 41237 40572.5 84709 32481.5 67995 45230 93867.5 58642	<$10,000=1378.82 $10,000-$14,999=1400.87 $15,000-$24,999=1297.15 $25,000-$34,999=1379.02 $35,000-$49,999=1305.58 $50,000-$74,999=1272.01 $75,000-$99,999=1142.99 >$100,000=1187.56	$c^2(7)$ =33.874, p=.000	(1&7)=(294.74, 245.08) (1&8)=(491.77, 425.32) (2&7)=(283.75, 233.16) (2&8)=(483.95, 412.74) (3&7)=(329.55, 292.11) (3&8)=(514.44, 474.15) (4&7)=(323.78, 269.26) (4&8)=(520.64, 450.54) (5&7)=(346.63, 305.27) (5&8)=(534.63, 487.08) (6&7)=(381.94, 343.16)	z=-3.515 (1&7) z=-3.058 (1&8) z=-3.551 (2&7) z=-3.144 (2&8) z=-2.584 (3&7) z=-1.989 (3&8) z=-3.823 (4&7) z=-3.402 (4&8) z=-2.803 (5&7) z=-2.369 (5&8) z=-2.493 (6&7)	p=.000 p=.002 p=.000 p=.002 p=.010 p=.047 p<.001 p=.001 p=.005 p=.018 p=.013

Table 9. Continued

Predictor	DV	Mann Whitney U	MWU Mean rank	Kruskal-Wallis	KW Mean rank (with Mann Whitney comparison)	z-approximation test	p-value
Annual Income	dating intention	N/A	<$10,000=1306.99 $10,000-$14,999=1263.98 $15,000-$24,999=1172.97 $25,000-$34,999=1331.16 $35,000-$49,999=1242.05 $50,000-$74,999=1259.37 $75,000-$99,999=1278.09 >$100,000=1257.99	$c^2(7) = 7.04$	N/A	N/A	p>.05
	marital intention	N/A	<$10,000=1279.05 $10,000-$14,999=1282.95 $15,000-$24,999=1203.39 $25,000-$34,999=1333.22 $35,000-$49,999=1268.29 $50,000-$74,999=1277.74 $75,000-$99,999=1265.32 >$100,000=1234.86	$c^2(7) = 5.272$	N/A	N/A	p>.05
	childbearing intention	N/A	<$10,000=1232.45 $10,000-$14,999=1306.21 $15,000-$24,999=1217.28 $25,000-$34,999=1347.98 $35,000-$49,999=1221.97 $50,000-$74,999=1269.59 $75,000-$99,999=1257.09 >$100,000=1258.97	$c^2(7) = 5.91$	N/A	N/A	p>.05

Racial/ethnic groups also differed regarding dating [$\chi^2(2) = 75.549$, $p<.001$], marital [$\chi^2(2) = 50.13$, $p<.001$], and childbearing [$\chi^2(2) = 22.418$, $p<.001$] intentions. White/Caucasians; had, on average, significantly higher intentions to date (Dating intention, Mean rank=1346.6) and marry (Marital intention Mean rank=1329.65) indviduals of varying genetic status than Hispanic/Latinos (Dating intention Mean rank=1141.47, z=-5.538, p<.001; Marital intention Mean rank=1172.32, z=-4.237, p<.001) or Others (Dating intention Mean rank=1022.64, z=-7.642, p<.001; Marital intention Mean rank=1059.51, -6.386, p<.001). Hispanic/Latinos and Others also significantly differed in dating (z=-2.532, p=.011) and marital (-2.34, p=.019) intentions. White/Caucasians (Mean rank=1306.06) also had significantly higher childbearing intentions than Hispanic/Latinos (Mean rank=1206.92, z=-2.685, p=.007) or Others (Mean rank=1122.02, z=-4.334, p<.001). There were no significant differences between Hispanic/Latinos and Others in terms of childbearing intentions.

Marital Status

Perceptions of genetic risk for developing specific genetic and genetic-linked disorders were assessed based on marital status (see Table 9). Marital groups did not differ in terms of perception of genetic risk [$\chi^2(3) = 1.86$, $p>.05$], or dating [$\chi^2(3) = 2.02$, $p>.05$] and childbearing [$\chi^2(3) = 5.77$, $p>.05$] intentions. A significant difference emerged between groups in terms of marital intention [$\chi^2(3) = 7.95$, $p=.047$]. Those who were married had significantly higher intention to marry individuals who were carriers

or affected by a genetic disorder (Mean rank=447.99) than those who were short-term dating (Mean rank=401.86, z=-2.7, p=.007).

Religious or Spiritual Preference

Religious or spiritual preference also moderated perceptions of genetic risk, among this sample (See Table 9). There were no differences between religious/spiritual preference groups in terms of perception of genetic risk [$\chi^2(2) = 1.836$, $p > .05$]. Groups also did not differ in terms of dating [$\chi^2(2) = 5.424$, $p > .05$] or marital [$\chi^2(2) = 1.943$, $p > .05$] intentions. A significant difference emerged between groups in terms of childbearing intention [$\chi^2(2) = 6.477$, $p = .039$]. Those who were practicing Protestants (Mean rank=1023.33) had significantly higher intention to have children with individuals of varying genetic status than those who practiced other religions (Mean rank=934.14, z=-2.186, p=.029).

Annual Income

Annual income also moderated perceived risk for developing specific genetic and genetic-linked disorders [See Table 9; $\chi^2(7) = 33.874$, $p < .001$]. Individuals who reported incomes less than $35,000 per year perceived their risk as significantly higher, on average, than those reporting incomes of "$75,000-$99,999" and "greater than $100,000." In addition, individuals reporting incomes of "$50,000-$74,999" perceived their genetic risk as signifcantly higher than those reporting "$75,000-$99,999." There

were no differences between income groups based on dating [$\chi^2(7) = 7.04$, $p > .05$], marital [$\chi^2(7) = 5.272$, $p > .05$], and childbearing intention [$\chi^2(7) = 5.91$, $p > .05$].

Question # 2: "Which theory-based variables predict sexual and reproductive intention by college students?"

A multiple regression analysis was conducted to answer this question. Predictors were demographic variables (e.g., age, gender, marital status, racial/ethnic heritage), Health Belief Model variables (i.e., perceived risk, perceived severity, perceived barriers, and perceived benefits), and Theory of Planned Behavior variables (i.e., social norms, attitudes, and perceived behavioral control). Three regression models were created for each intention (to date, marry, or bear children). The first model contained only demographic predictor variables and a specific intention variable. The second model contained a set of demographic variables and HBM variables, and the intention variable. The third model contained a set of demographic, HBM, and TPB variables, and the the intention variable. Significance was assessed by $p < .05$.

Dating Intention

In order to assess predictors of our sample's dating intentions, the first regression model contained only the demographic variables age, gender, marital status, racial/ethnic heritage, parenting status, religious/spiritual preference, religiosity, religious/spiritual service attendance, educational status, educational attainment, biology/genetics major, and annual income (See Table 10). This set of demographic variables was significantly

Table 10 Multiple Regression Models of Dating Intention

Predictors	Model 1 Adjusted R^2 = .038 B (95% CI)	p	Model 2 Adjusted R^2 = .069 B (95% CI)	p	Model 3 Adjusted R^2 = .373 B (95% CI)	p
Gender	0.042 (.032, .77)	.033*	0.071 (.308, 1.043)	.000**	0.074 (.396, 1.003)	.000**
Race/Ethnic Heritage	-0.174 (-2.06, -1.26)	.000**	-0.152 (-1.845, -1.05)	.000**	-0.044 (-.750, -.084)	.014*
Educational Status	0.093 (.39, 1.671)	.002**	0.058 (.006, 1.28)	0.048*		
Parenting Status	-0.072 (.955, 1.085)	.006**	-0.071 (-1.817, -.302)	.006**		
Perceived Severity			-0.079 (-.048, -.015)	.000**		
Perceived Barriers			-0.124 (-.137, -.069)	.000**		
Perceived Benefits			-0.052 (-.107, -.013)	.013*		
Family Dating Norms					0.261 (.238, .342)	.000**
Friend Dating Norms					0.225 (.213, .323)	.000**
Dating Beliefs					0.146 (.136, .225)	.000**
Dating Values					-0.113 (-.156, -.077)	.000**

*=p<.05

**=p<.01

related to dating intention [F(12, 2479)=9.112, p<.001]. The adjusted R^2 value was .038, indicating that approximately 3.8% of the variance in dating intention can be accounted for by this set of demographic variables. Significant individual demographic predictors included gender (β=.042, p=.033), race/ethnic heritage (β=-.174, p<.001), educational status (β=.093, p=.002), and parenting status (β=-.072, p=.006). Gender and educational status were positively associated with dating intentions, meaning that female gender and status as a graduate/professional was associated with an increase in dating intention. The converse was true for race/ethnic heritage and parenting status. Other race/ethnic heritage or having a biological child was associated with lower dating intentions.

The second regression model added a set of HBM predictors to Model 1 (See Table 10). The HBM and demographic predictors were significantly related to dating intention and accounted for 6.9% of the total variance [F(16, 2475)=12.50, p<.001; adjusted R^2=.069) This change in variance represents an increase of 3.1% over Model 1. Significant individual demographic and HBM predictors included gender (β=.071, p<.001), race/ethnic heritage (β=-.152, p<.001), educational status (β=.058, p=.048), parenting status (β=-.071, p=.006), perceived severity (β=-.079, p<.001), perceived barriers (β=-.124, p<.001), and perceived benefits (β=-.052, p=.013). In this model, perceived severity, perceived barriers, and perceived benefits were negatively associated with dating intention. Respondents who perceived that the severity of a genetic disorder was high were less likely to date someone who was a carrier or affected by a genetic disorder. In addition, respondents who perceived stronger barriers (obstacles) or greater

benefits (advantages) to having healthy children had decreased dating intention related to these individuals.

The third regression model added TPB predictors to the demographic and HBM variables in Model 2 (See Table 10). This set of variables was significantly related to, and accounted for approximately 37.3% of variance in, dating intention [$F(21, 2470)=71.44$, $p<.001$; adjusted $R^2=.373$). This represented a substantial increase in the strength of the linear relationship between predictors and intention ($R=.615$), as well as an increase in accounted-for-variance of 30.4%. Significant individual predictors within this model included gender ($\beta=.074$, $p<.001$), race/ethnic heritage ($\beta=-.044$, $p=.014$), family dating norms ($\beta=.261$, $p<.001$), friend dating norms ($\beta=.225$, $p<.001$), dating beliefs ($\beta=.146$, $p<.001$) and dating values ($\beta=-.113$, $p<.001$). In this model, family and friend dating norms and dating beliefs were positively associated with dating intention. Greater approval in social norm areas and more positive beliefs concerning dating a carrier or affected individual were associated with higher dating intention. However, dating values (i.e., the perceived "importance" of dating these individuals) were negatively associated with dating intention. Values assigning lower importance to dating a carrier or affected indvidual were associated with stronger dating intention.

Marital Intention

To assess predictors of our sample's marital intentions, an initial regression model was run, only with the demographic variables (See Table 11). This set of demographic variables was significantly related to marital intention [$F(12, 2479)=6.30$,

Table 11. Multiple Regression Models of Marital Intention

Predictors	Model 1 Adjusted R^2 = .025 □ (95% CI)	p	Model 2 Adjusted R^2 = .061 . □ (95% CI)	p	Model 3 Adjusted R^2 = .392 . □ (95% CI)	p
Gender			0.054 (.150, .955)	.007**	0.061 (.305, .956)	.000**
Race/Ethnic Heritage	-0.146 (-1.958, -1.08)	.000**	-0.126 (-1.749, -.878)	.000**		
Educational Status	0.066 (.103, 1.508)	.025*				
Parenting Status	-0.072 (-2.015, -.325)	.007**	-0.07 (-1.965, -.307)	.007**		
Marital Status	0.05 (.023, 1.436)	.043*				
Perceived Severity			-0.098 (-.060, -.025)	.000**		
Perceived Barriers			-0.106 (-.137, -.059)	.000**		
Perceived Benefits			-0.079 (-.153, -.049)	.000**		
Perceived Risk					0.039 (.002, .019)	.016*
Family Marital Norms					0.244 (.224, .335)	.000**
Friend Marital Norms					0.214 (.202, .317)	.000**
Marital Beliefs					0.147 (.133, .220)	.000**
Marital Values					-0.166 (-.156, -.077)	.000**

*=p<.05, **=p<.01

p<.001]. The adjusted R^2 was .025, thus, 2.5% of the variance in marital intention can be accounted for by this set of demographic variables. Significant individual demographic predictors included marital status (β=.050, p=.043), race/ethnic heritage (β=-.146, p<.001), educational status (β=.066, p=.025), and parenting status (β=-.072, p=.007). Educational status was positively associated with marital intentions, meaning that status as a graduate or professional student was associated with an increase in marital intention. Conversely, race/ethnic heritage and parenting status were negatively associated with marital status. Other race/ethnic heritage or having a biological child was associated with lower marital intentions.

The second regression model contained the set of demographic variables, and HBM predictors (See Table 11). These predictors (combined) were significantly related to marital intention and accounted for 6.1% of variance [F(16, 2475)=11.15, p<.001; adjusted R^2=.061) This change in variance repersents an increase of 3.6% over Model 1. Significant individual demographic and HBM predictors included gender (β=.054, p=.007), race/ethnic heritage (β=-.126, p<.001), parenting status (β=-.070, p=.007), perceived severity (β=-.098, p<.001), perceived barriers (β=-.106, p<.001), and perceived benefits (β=-.079, p<.001). Gender was the only positively associated variable in the model. Female gender was associated with an increase in marital intention. The remaining variables in the model were negatively associated with intention. Other race/ethnic heritage and having a biological child were associated with lower marital intention. Further, weak perceived barriers and benefits to having healthy

children, and lower severity of genetic disorders, were associated with an increase in marital intention towards individuals who are carriers or affected by a genetic disorder.

The third regression model contained the demographic, HBM, and TPB predictors (See Table 11). This linear combination of variables was significantly related to marital intention and accounted for approximately 39.2% of the variance in marital intention [$F(21, 2470)=77.48$, $p<.001$; adjusted $R^2=.392$). This represented a substantial increase in the strength of the linear relationship between predictors and intention ($R=.630$), as well as an increase in accounted-for-variance of 33.1%. Significant individual predictors within this model included gender ($\beta=.061$, $p<.001$), family marital norms ($\beta=.244$, $p<.001$), friend marital norms ($\beta=.214$, $p<.001$), marital beliefs ($\beta=.147$, $p<.001$), marital values ($\beta=-.166$, $p<.001$), and perceived risk ($\beta=.039$, $p=.016$). Gender, social norms, marital attitudes, and risk perceptions were positively associated with marital intention. Respondents who were female, had higher perceived risk, had supportive family and friends, and positive marital beliefs had higher marital intentions. Marital values were negatively associated with marital intentions. In this case, respondents who placed lower importance on marrying indviduals who are carriers or affected by genetic disorder had stronger marital intention.

Childbearing Intention

In order to assess predictors of our sample's childbearing intentions we performed multiple regression analyses (See Table 12). The set of demographic variables in Model 1 was significantly related to childbearing intention [F(12,

Table 12. Multiple Regression Models of Childbearing Intention

Predictors	Model 1 Adjusted R^2 = .026 B (95% CI)	p	Model 2 Adjusted R^2 = .087 B (95% CI)	p	Model 3 Adjusted R^2 = .387 B (95% CI)	p
Age	-0.077 (-.106, -.015)	.009**	-0.071 (-.100, -.012)	.013*	-0.5 (-.075, -.003)	.035*
Gender					0.039 (.082, .768)	.015*
Race/Ethnic Heritage	-0.102 (-1.571, -.653)	.000**	-0.078 (-1.296, -.398)	.000**		
Educational Status	0.071 (.166, 1.636)	.016*				
Religion/Spiritual Preference	-0.077 (.398, 1.293)	.000**	0.081 (.453, 1.321)	.000**	0.033 (.009, .723)	.044*
Religiosity	0.076 (.132, .706)	.004**	0.07 (.107, .664)	.007**		
Perceived Severity			-0.093 (-.061, -.024)	.000**		
Perceived Barriers			-0.162 (-.193, -.116)	.000**		
Perceived Benefits			-0.106 (-.194, -.087)	.000**		

Table 12. Continued

Predictors	Model 1 Adjusted R^2 = .026 B (95% CI) p	Model 2 Adjusted R^2 = .087 B (95% CI) p	Model 3 Adjusted R^2 = .387 B (95% CI) p
Child Perceived Behavioral Control			-0.052 (-.033, -.008) .001**
Family Childbearing Norms			0.2 (.172, .285) .000**
Friend Childbearing Norms			0.179 (.155, .270) .000**
Childbearing Beliefs			0.216 (.175, .255) .000**
Childbearing Values			-0.128 (-.188, -.098) .000**

2479)=6.50, p<.001]. The adjusted R^2 value was .026, indicating that approximately 2.6% in childbearing intention can be accounted for by the set of demographic variables. Significant demographic predictors included age (β=-.077, p=.009), race/ethnic heritage (β=-.102, p<.001), religious/spiritual preference (β=-.077, p<.001), religiosity (β=.076, p=.004), and educational status (β=.071, p=.016). Religiosity and educational status were positively associated with childbearing intention. Those who considered themselves more religious/spiritual, and were pursuing graduate/professional education had higher childbearing intentions. In contrast, those who were Other race/ethnic heritage and Other religious/spiritual preference had lower childbearing intention.

The set of predictors in Model 2 (containing demographic and HBM variables) was significantly related to childbearing intention and accounted for 8.7% of variance [F(16, 2475)=15.81, p<.001; adjusted R^2=.087) This change in variance represents an increase of 6.1% over Model 1. Significant individual demographic and HBM predictors included age (β=-.071, p=.013), race/ethnic heritage (β=-.078, p<.001), religious/spiritual preference (β=.081, p<.001), religiosity (β=.070, p=.007), perceived severity (β=-.093, p<.001), perceived barriers (β=-.162, p<.001), and perceived benefits (β=-.106, p<.001). Religious/spiritual preference and religosity were postively associated with childbearing intentions. Christian religious/spiritual preference and indviduals perceiving themselves as religious or spiritual persons had higher childbearing intention. Further, younger age, Other race/ethnic heritage, weak perceived barriers and benefits to having healthy children, and lower severity of genetic disorders,

were associated with an increase in childbearing intention (i.e., having a child with individuals who are carriers or affected by a genetic disorder).

The third regression model contained all of the predictors (demographic, HBM and TPB variables) and was significantly related to childbearing (See Table 12). Model 3 accounted for approximately 38.7% of variance in childbearing intention [$F(21, 2470)=75.89$, $p<.001$; adjusted $R^2=.387$). This represented a substantial increase in the strength of the linear relationship between predictors and intention ($R=.626$), as well as an increase in accounted-for-variance of 30.0%. Significant predictors within this model included age ($\beta=-.050$, $p=.035$), gender ($\beta=.039$, $p=.015$), religious/spiritual preference ($\beta=.033$, $p=.044$), family childbearing norms ($\beta=.200$, $p<.001$), friend childbearing norms ($\beta=.179$, $p<.001$), child perceived behavioral control ($\beta=-.052$, $p=.001$), childbearing beliefs ($\beta=.216$, $p<.001$) and childbearing values ($\beta=-.128$, $p<.001$). Age, perceived behavioral control over childbearing, and childbearing values were negatively associated with childbearing intention. Younger respondents and those who perceived that they had less control over who they had children with, or weaker values concerning this choice, were more likely to have stronger childbearing intentions. Respondents who were Christian, had family and friends who were in agreement, or positive beliefs concerning childbearing with individuals of varying genetic status, were more likely to have stronger childbearing intentions.

Discussion

The current study contributes to the literature in three ways. First, it bridges a gap between evolutionary psychology and social cognitive and behavioral theory. Human mate selection has been studied extensively within the field of evolutionary psychology. However, as previously mentioned, few studies have explored mate selection apart from describing "a catalogue of cues" related to physical attractiveness, sex differences, personality or parental investment (Miller, 1997, pp. 72-73). Exploring complementary or alternative theories to the dominant evolutionary psychology paradigm provides genetic and health education researchers with a wider range of frameworks for designing future studies, interpreting existing data, and planning prevention/health promotion programs.

In combining and testing HBM and TPB variables, this study makes additional contributions to the literature. The study utilized mixed methods to design a theory-based instrument. Themes emerging from qualitative inquiry were analyzed using existing theory and used as the basis for survey items and scales/subscales. In this way, the instrument was "grounded" in established theoretical constructs, as well as the socio-environmental context of the population of interest.

Next, data collected using this theory-based instrument were tested using multivariate analyses. Rather than relying solely on descriptive, univariate, bivariate, or multiple single predictor-outcome variable analyses, multivariate techniques allowed the investigator to: 1) simultaneously examine relationships among multiple predictors and an outcome variable, and 2) assess the unique contributions of each variable and its

impact on the collective model. Multivariate techniques provide better models of increasingly complex relationships between variables of differing ecological levels, paving the way for more accurate and powerful analysis (Roberts, 2004; wa-Kivilu, 2003).

Results from univariate and multiple regression analyses indicate that a number of demographic and social cognitive variables influence genetic risk perceptions and sexual and reproductive intentions among the sample studied. Demographic variables that influenced this relationship included age, gender, race/ethnic heritage, religious/spiritual preference, religiosity, parenting status, and educational status. Theory of Planned Behavior variables were the strongest predictors of intention in this sample. Family dating norms were the single best predictor in the dating and marital intention models. Positive family norms predicted intention to date, marry, or have children with individuals of diverse genetic status.

A number of studies have explored this link between family norms, genetic risk perceptions, and sexual and reproductive intentions and behaviors (Holt, 2006; Sobel & Cowan, 2000; Werner-Lin, 2007). Genetic risk perceptions are highly subjective and contextualized. Strong, supportive norms exert a significant influence on members of a social group. Social norms reinforce group rules, mores, and identity. Thus, norms also have the power to influence individual perceptions and attitudes (Fishbein & Ajzen, 1975). Attitudinal values and beliefs were also strong predictors of intention in this sample.

When combined, TPB variables accounted for 33.1-38.7% of the variance in dating, marital, or dating intention in this sample. Empirical studies and meta-analytic reviews of the TPB (and related Theory of Reasoned Action) provide support for its *predictive power* across a number of health behaviors, populations and contexts (Armitage & Conner, 2000; Conner & Abraham, 2001; Montano & Kasprzyk, 2002). Increased use of TPB constructs reflects the idea that the theory is rather well defined, and relatively easy to operationalize and incorporate into research studies. The theory also contains a small number of constructs and paths. When combined, these features may provide a higher level of *specificity* and *parsimony* than other theories.

While the HBM constructs did not emerge as strong predictors of dating, marrying and childbearing intentions in our analyses, the HBM is considered the most *influential* and empirically supported theoretical framework for health behavior and genetic screening studies (Gooding et al., 2006; Roden, 2004). Part of the reason for its widespread use in this field may attest to the importance of perceived risk as a predictor of health behavior. According to Katapodi et al. (2004), "perceived risk is an important motivator for protective health-related behaviors…(there is a) need to understand associations between perceived risk, psychosocial characteristics, and the way in which perceived risk acts as a motivator for these behaviors" (p. 397).

Even so, meta-analytic and empirical reviews of the overall HBM report mixed results. Armitage and Conner (2000) catalog a range of concerns including small effect sizes, weak correlations between HBM constructs and behavior; and a lack of rules for combining HBM components. HBM variables' performance in this study's multiple

regression models supports these findings. Overall, these variables were weak predictors and accounted for only 3.1-6.1% of variance in dating, marital, or childbearing intention. Perception of genetic risk was positively, but weakly, associated with marital intention (marital intention Model 3); this represents the only appearance of perceived risk in any of the intention models.

Limitations

The proposed study contains several limitations related to study design, data collection, and statistical analyses. The *cross-sectional* nature of the design makes causal inferences pertaining to the relationship between predictors and outcome variables difficult. Intention was measured in lieu of actual sexual and reproductive decision-making, as these decisions tend to occur over time.

Respondents may have also introduced selection bias into the study. Recruitment e-mails were sent to all enrolled students, ages 18 or older, at each site. While researchers offered modest incentives for participation (i.e., opportunities to participate in a random drawing for gift cards and movie tickets), the survey itself took approximately 20 minutes to complete. Given that not every participant will receive compensation for participating in this study, researchers are unsure what motivated participants' decisions concerning "opting in" and completing the study or opting out.

What is known, is that this study sample consisted primarily of single, young, Christian, females, that it was neither representative of the university communities from which it was selected, nor of higher education in general. Further, it is unclear how

much of the statistical analysis issues surrounding univariate and multivariate non-normality are functions of participants' demographic and social characteristics or the variables being measured. A related issue, then, is the large sample size and its potential for artificially inflating test statistics and effectively rendering "false positives" on variables that may not be relevant in the wider population of students or society (Thompson, 2006).

Finally, limitations related to web-based survey research include the assumptions that a large portion of the intended population owns or has access to a computer; is well versed in its use; and feels comfortable with participating in online surveys. An additional limitation results from survey deployment using non-university resources. Surveys were deployed *en masse* from a third party service, a reminder followed one-week later. The volume and source of mass e-mails may have caused university servers to "bounce" (return) messages to the online survey service, thus preventing message delivery (C. Boatwright, TAMU, personal communication, May 20, 2008). As a result, an undetermined segment of students targeted for recruitment may have failed to receive invitation e-mails.

Since not all eligible participants received the initial or reminder e-mails, accurately calculating a response rate is difficult. The calculated response rates were low (~3%). Yet, it is unclear how much of this low response was due to failure to send multiple reminders (i.e., the more common practice, Dillman, 2007), length of the survey and time for completion, time of deployment (i.e., two weeks prior to semester final exams), or other factors (e.g., objections to subject matter).

Implications for Practice

This study has implications for research and practice. First, this study is one of the first to build and test a theory-based instrument based on qualitative data, focusing on the topic of perceptions of genetic risk and reproductive behaviors/mate selection. Results of this study may be used to aide understanding of the complex phenomenon that is mate selection. Knowledge concerning psychosocial and theory-based variables that influence genetic risk perceptions and specific sexual/reproductive intentions may stimulate additional studies that bridge the gap between evolutionary psychology and social cognitive and behavioral research.

Second, results of this study provide "food for thought" concerning how individuals acquire, interpret, and utilize risk perceptions in forming sexual/reproductive intentions and behaviors. Study results suggest a need for continuing genetics education during the reproductive/developmental span. A number of genetic risk and screening interventions begin post-conception; however, intentions related to dating, marrying, and having children with individuals who are carriers or affected by a genetic disorder precede this event. Pre-conception interventions in the form of genetic health awareness and literacy building efforts may be warranted (Werner-Lin, 2007). Potential entry points for intervention may include long-term dating, engaged, and newly married couples.

Genetic health education efforts should be tailored to the population of interest. The number of significant predictor demographic variables identified in this study illustrates the need for gender and culturally sensitive interventions. Significant

religious/spiritual preference and religiosity predictors of behavioral intention make religious/spiritual preference another sensitive, but potentially, effective point of intervention. Considering potential participants' religious/spiritual preferences and explicit religious doctrines concerning sexual/reproductive decision-making may prove helpful when attempting to design religious/spiritually-sensitive interventions.

And finally, this research study may aid in increasing dialogue among fields whose research overlaps with genetic risk perceptions and sexual/reproductive intentions and behavior. Multidisciplinary collaboration among fields as diverse as genetics, education, psychology, philosophy, sexual sciences, and public health may lead to more rapid advances in the science, technology, and ethics of genetic risk perceptions and sexual/reproductive decision-making.

CHAPTER V

CONCLUSION

Findings from the systematic literature review (presented in Chapter II) contribute to the genetic risk and sexual/reproductive health literature in two ways. This review appears to be one of the first to study an array of demographic, psychosocial, and genetic-testing factors that influence the relationship between perception of genetic risk and human mate selection. Previous reviews have explored these factors independently or in combination with either perception of genetic risk or mate selection variables. Second, this review further contributes to the literature by summarizing and describing factors related to the variables of interest, and provides an analysis of the conceptual and methodological quality of the reviewed studies.

The review of 26 empirical studies identified almost 50 individual psychosocial, family psychosocial, demographic, or genetic testing-related factors exerting an influence on perception of genetic risk and mate selection. Individual psychosocial factors included positive, negative, and bi-directional/mixed associations among factors and the variables of interest. Intentions (i.e., marital, childbearing) represented the largest group within these types of factors. Other individual psychosocial factors included accuracy of knowledge related to specific genetic disorders, views on abortion, attitude towards inheriting a genetic disorder, as well as perceived severity or benefits of reproductive outcomes. Most (75%) familial psychosocial factors were positively associated with the variables of interest including level of family support, social support

(in general), and cautions about familial risk for inheriting disorders during childhood. Demographic factors included age, gender, and religion; more demographic findings had a bi-directional/mixed or negative association with the variables of interest than positive. Over three quarters (77.3%) of findings related to genetic testing contained a negative association with the variables of interest. For example, higher perceptions of genetic tests' efficacy led to lower perceptions of genetic risk and less conservative mate selection

While the nature and type of influence differed, the largest number of findings in this systematic review involved bi-directional associations. Higher number of bi-directional or inconclusive findings in this area may reflect the highly subjective and contextualized situations in which these types of risk-related decisions are being made. Future studies should also continue to explore the demographic, psychosocial, and genetic-testing factors that influence the relationship between perception of genetic risk and mate selection. Exploratory studies that focus on young adult males and females of diverse racial and ethnic backgrounds, prior to marriage and pregnancy would expand the literature. Such expansion would provide a solid foundation for health education and prevention-based programs.

Chapter III presented findings from a qualitative study of perceptions of genetic risk and sexual/reproductive decision-making. A large number of participants were graduate-level students in health education, kinesiology, social work, or a science/engineering-field. They were also part of a predominately young, female, single, never married, and Christian sample.

Overall, participants exhibited a moderate level of verbal and knowledge-based health literacy when interpreting and discussing genetic risk information, even when they were unfamiliar with its mechanisms. Yet, this information periodically contained inaccuracies. Participants sometimes attributed individual characteristics to genetic inheritance.

Further, participants misinterpreted numerical genetic risk, seeing this concept more in terms of absolute risk rather than as a fluid, changing, and complex calculation. Their risk perceptions and understanding of this information appeared to be grounded more in highly contextualized personal, familial, or social narratives than in the scientific literature.

Responses to focus group questions asking participants to operationalize genetic risk as it influences sexual/reproductive decision-making resulted in descriptions of the often-conflicting psychosocial and contextual factors that contribute to these types of decisions. Diversity in participants' age, gender, race/ethnicity, marital status, religious preference, and exposure to genetic concepts and technology, as well as social, emotional, economic, and health factors, appeared to influence dating, marital, and childbearing decisions.

This study demonstrated that qualitative methodologies are particularly useful for determining how groups think and why they behave in specific ways. Further qualitative research needs to be performed to understand the positive and negative impact that participation in social groups might have on sensitive decisions such as those involved in sexual and reproductive health. Health professionals need to have an understanding of

family, friend, and other normative group dynamics in order to counter decisions based on misinformation or poor health literacy.

Chapter IV presented findings from a quantitative web-based survey of perceptions of genetic risk and sexual/reproductive intention. Intention was measured in lieu of actual sexual and reproductive decision-making. As these decisions tend to occur over time, measuring actual decision-making was inappropriate for this one-shot case (cross-sectional) study.

The study utilized mixed methods to design a theory-based instrument. Themes emerging from qualitative inquiry were analyzed using existing theory and used as the basis for survey items and scales/subscales. Data collected using this theory-based instrument were tested using multivariate analyses in lieu of relying solely on univariate or bivariate analyses. Previous research has demonstrated multivariate techniques' value in providing better models of increasingly complex relationships between variables of differing ecological levels (Roberts, 2004; wa-Kivilu, 2003).

Results from univariate and multiple regression analyses indicated that a number of variables influence genetic risk perceptions and sexual and reproductive intentions among the sample studied. Demographic variables that influenced this relationship included age, gender, race/ethnic heritage, religious/spiritual preference, religiosity, parenting status, and educational status. Theory of Planned Behavior variables were the strongest predictors of intention in this sample accounting for 33.1-38.7% of the variance. Positive family norms predicted intention to date, marry, or have children with

individuals of diverse genetic status and were the single best predictor of dating and marital intention.

The HBM constructs did not emerge as strong predictors of dating, marrying and childbearing intentions in multiple regression analyses. Overall, these variables were weak predictors and accounted for only 3.1-6.1% of variance in dating, marital, or childbearing intention. Perception of genetic risk was positively, but weakly, associated with marital intention.

The overall, mixed methods study has implications for the body of knowledge. Results of the systematic literature review and quantitative study, combined with qualitative findings, reveal that a number of demographic, psychosocial, and theoretical variables influence, and also predict, the relationships between genetic risk perceptions and sexual/reproduction intention and behavior. Demographic variables including age, gender, religion, race/ethnic heritage, religious/spiritual preference, religiosity, marital and parenting status appear to moderate this relationship. Additional moderators and mediators include family norms, perceived severity, perceived barriers, perceived benefits, values, beliefs, and perceived behavioral control. These novel qualitative and quantitative study findings affirm continued use of Theory of Planned Behavior, and to a lesser extent, Health Belief Model variables in empirical research studies of genetic risk perceptions and sexual/reproductive health behaviors.

Overall, study findings also affirm use of mixed methods designs for addressing research questions in the focal area. In terms of Methodological Quality Scores, mixed methods studies perform better on average than qualitative studies, and almost as well as

quantitative, epidemiological, and population-based studies. Analysis of the data collected using the web-based instrument indicate high internal consistency and, moderate to high, construct validity. Multiple regression analyses reveal moderately strong relationships between specific sets of demographic and theoretical variables identified using mixed methods data collection and incorporated into the full models (i.e., demographic, HBM, and TPB variables).

While the overall study design contains advantages due to mixing of paradigms, this mixed design also has limitations related to its mono-method components. One limitation of the qualitative phase pertains to the researcher's inability to identify individual participant responses based on demographic characteristics. Without participant-level detail, the researcher is unable to assess potential relationships between specific demographic variables and those of interest (e.g., age and sexual/reproductive intention and behavior). A quantitative phase limitation relates to its cross-sectional nature, which limits the study's ability to make causal inferences.

An additional limitation of the qualitative and quantitative phases relates to study generalizability. Each phase used non-random sampling. The resulting demographic characteristics were not reflective of the wider sampling frame. When sample chracteristics differ widely from the sampling frame, and samples are not randomly selected, generalizations cannot be made from the sample to the population. As a result, findings from the current study are not truly generalizable beyond this sample.

However, the findings do suggest important directions to follow in future research and health education and promotion intervention planning. Future studies

should focus on: 1) testing the emerging conceptual framework from Chapter IV using structural equation modeling; 2) analyzing the validity and internal consistency (reliability) of quantitative data collected from more representative and longitudinal samples; 3) utilizing mixed methods analyses and interpretations of existing qualitative and quantitative data; and 4) designing and implementing additional mixed methods studies in the focal area. Advanced multivariate analyses such as structural equation modeling will allow the researcher to simultaneously consider relationships between demographic, psychosocial, and theoretical variables, while also testing the predictive power of the model and of individual factors. Finally, given the relative importance of understanding how young adults conceptualize genetic risk and incorporate this understanding into sexual/reproductive behaviors, researchers should consider multiple cross-sectional or longitudinal designs when possible. While the systematic review criteria did not include a criterion in this area, a number of reviewed studies had cross-sectional designs, which are inadequate for establishing causal relationships.

Health education and promotion researchers who are interested in this emerging field may find mixed methods study design, sampling, data analysis and interpretation useful in addressing related research questions. Researchers may also want to explore additional psychosocial and theoretical variables for inclusion in the new conceptual model. For example, the current study did not measure or evaluate carrier status or intention to perform behaviors within a specific time frame.

Study findings also affirm a need for health educators to expand their practice to include genetic/genomic health. Chen, Kwok, and Goodson (in press) recommend that

health educators adopt genomic competencies into their practice. Health educators need not become specialists; however, increasing *capacity* in genomics is necessary for developing accurate and effective public health genomics programs and services. Instead, health educators should consider forming partnerships with local or regional genetic specialists (i.e., medical geneticists, genetic counselors) and health departments to create a continuum of care between health education programs and genetic services and technology.

A related finding pertains to the need for increasing genetic health literacy and awareness within the general public. Using newly adopted genomic competencies, health educators may create theory-based health education curricula, interventions, strategies, and community resource guides. The conceptual framework evaluated within this dissertation provides a potential model for program planning and evaluation.

Even so, practitioners should exercise caution prior to planning and implementing interventions based on this new conceptual framework. Based on study findings, interventions should be careful to consider issues related to gender, race/ethnic heritage, religious/spiritual preference, and related demographic variables as these variables strongly predicted sexual/reproductive intention in the quantitative phase and were associated with related behavior in the systematic review and qualitative phase of the study. Further, this model has not been tested with non-students; factors that influence or predict genetic risk perceptions and sexual/reproductive intentions may differ based on population.

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APPENDIX A. ALPHABETIZED LIST OF REVIEWED STUDIES*

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*Reviewed studies were alphabetized and assigned a number, 1-26. The numbers in brackets in the systematic review and in Appendiz A are the study numbers.

APPENDIX B. INTERVIEW GUIDE FOR FOCUS GROUPS

Research question: How does perception of genetic risk influence sexual and reproductive decision-making by college students?

Defining genetics:

1. When I say "genetics," what, if anything, comes to mind? (Lanie et al., 2004)
2. When someone says that an ability, behavior, characteristic, or problem is "genetic," what does this mean? (Lanie et al., 2004)
3. Lots of medical conditions can be directly linked to a person's genes or genetic makeup. Some like Sickle Cell Anemia and hemophilia can directly affect the blood. Some like Down's syndrome can directly lead to physical or mental disabilities. Still others may lead to medical problems such as cancer, depression, and diabetes. Are some genetic disorders "better" to have than others?
4. When you need or want genetic information, where do you get it?
5. What factors may influence whether someone will manifest a genetic ability, behavior, or characteristic?

Defining "genetic risk":

Let's take a look at one very unique family and their experiences living with a genetic disorder.

[Show 5-8 minutes of excerpts from the Discovery Health Channel documentary titled "Dwarf Family: Meet the Fooses."]

[The Fooses (Joe, Ginny, Alex, Ben, and Dasha) are "a typical American family in almost every way except one- they are all dwarfs. This determined family of five has been able to overcome physical limitations and social stigmas associated with achondroplasia, the medical term for their condition." The show first aired on January 9, 2006 and is rated "G" (Discovery Health Channel website).]

6. Everyone takes risks at some point in their lives whether they are changing jobs, playing poker, engaging in hobbies like bungee jumping, etc. As you saw in the video, the Foos family took some risks when deciding to have children. When I say the term "genetic risk," what, if anything, comes to mind?
7. If you knew that someone in your family had a genetic disorder or a health problem related to genetics, how would you feel?
   Probe= Without getting into specific issues, would you feel like you are also at risk of developing the same genetic disorder or health problem?
8. In the video, Ginny Foos explains that she and Joe had a 25% chance of having a non-dwarf child, a 50% chance of having a dwarf child, and a 25% chance of passing on a "double whammy" or lethal form of dwarfism. Risk of developing

or passing on a genetic disorders are often explained using numbers or percentages, but this "language" may be confusing.

Which of the following phrases makes more sense to you and why? "Someone has a 25% chance of developing a genetic disorder." "Someone has a 1 in 4 chance of developing a genetic disorder." "Someone has a 75% chance of not developing a genetic disorder." "Someone has a 3 in 4 chance of not developing a genetic disorder."

Probe= Which of these statements sounds negative?

Probe= Which of these statements sounds positive?

Genetic risk and sexual and reproductive decision-making:

9. Sometimes when we make decisions, we aren't completely sure (we're uncertain) about what the outcome or consequences will be. What types of factors would influence your decision to date or marry someone?
10. What types of health-related factors would influence your decision to have children with someone?
11. If someone knew about you family tree/history, do you think that might influence their decision to date or marry you?
12. If you knew your family tree/history, how might this influence your decisions to have children?
13. How would knowledge of someone's family tree/history influence your decision to date or marry them?
14. How would knowledge of someone's family tree/history influence your decision to have children with them?
15. In the future, genetic testing may become so specific that we could do things like select children's eye color before they are born or determine if they might have a learning disability. Do you foresee any benefits or problems that might occur because of this type of genetic testing?

    Probe= Where would you draw the line?

APPENDIX C. INSTITUTIONAL REVIEW BOARD DOCUMENTS

TEXAS A&M UNIVERSITY
VICE PRESIDENT FOR RESEARCH - OFFICE OF RESEARCH COMPLIANCE

1186 TAMU
College Station, TX 77843-1186
1500 Research Parkway, Suite B-150

979.458.1467
FAX 979.862.3176
http://researchcompliance.tamu.edu

Institutional Biosafety Committee | Institutional Animal Care and Use Committee | Institutional Review Board

DATE: 15-Jun-2007

MEMORANDUM

TO: GOODSON, PATRICIA
TAMU-HEALTH & KINESIOLOGY(00047)

FROM: Office of Research Compliance
Institutional Review Board

SUBJECT: Request for Continuation

Protocol Number:	2006-0366
Title:	Perception of Genetic Risk in Decision-Making (PGRID) by College Students
Review Category:	Expedited
Approval Period:	18-Jul-2007 **To** 17-Jul-2008

Approval determination was based on the following Code of Federal Regulations:

45 CFR 46.110(b)(1) - Some or all of the research appearing on the list and found by the reviewer(s) to involve no more than minimal risk.
---
(7) Research on individual or group characteristics or behavior (including, but not

limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation or quality assurance methodologies.

(Note: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b) (3). This listing refers only to research that is not exempt.)

Provisions:

This research project has been approved for one (1) year. As principal investigator, you assume the following responsibilities

1. **Continuing Review:** The protocol must be renewed each year in order to continue with the research project. A Continuing Review along with required documents must be submitted 30 days before the end of the approval period. Failure to do so may result in processing delays and/or non-renewal.
2. **Completion Report:** Upon completion of the research project (including data analysis and final written papers), a Completion Report must be submitted to the IRB Office.
3. **Adverse Events:** Adverse events must be reported to the IRB Office immediately.
4. **Amendments:** Changes to the protocol must be requested by submitting an Amendment to the IRB Office for review. The Amendment must be approved by the IRB before being implemented.
5. **Informed Consent:** Information must be presented to enable persons to voluntarily decide whether or not to participate in the research project.

TEXAS A&M UNIVERSITY
DIVISION OF RESEARCH AND GRADUATE STUDIES - OFFICE OF RESEARCH COMPLIANCE

1186 TAMU
College Station, TX 77843-1186
1500 Research Parkway, Suite B-150

979.458.1467
FAX 979.862.3176
http://researchcompliance.tamu.edu

Institutional Biosafety Committee | Institutional Animal Care and Use Committee | Institutional Review Board

DATE: 25-Mar-2008

MEMORANDUM

TO: GOODSON, PATRICIA

FROM: Office of Research Compliance
Institutional Review Board

SUBJECT: Amendment

Protocol Number:	2006-0366
Title:	Perception of Genetic Risk in Decision-Making (PGRID) by College Students
Review Category:	Expedited
Approval Period:	25-Mar-2008 **To** 17-Jul-2008

Approval determination was based on the following Code of Federal Regulations:

45 CFR 46.110(b)(2) - Minor changes in previously approved research during the period of (one year or less) for which approval is authorized.

Provisions: Compensation changed to $5 movie gift card from 2 movie tickets. Info

sheet and recruitment flyer updated accordingly. Development and distribution of PGRID survey approved. Final version must be approved via amendment prior to distribution if there are any changes made as a result of the instrument development phase.

This research project has been approved for one (1) year. As principal investigator, you assume the following responsibilities

1. **Continuing Review:** The protocol must be renewed each year in order to continue with the research project. A Continuing Review along with required documents must be submitted 30 days before the end of the approval period. Failure to do so may result in processing delays and/or non-renewal.
2. **Completion Report:** Upon completion of the research project (including data analysis and final written papers), a Completion Report must be submitted to the IRB Office.
3. **Adverse Events:** Adverse events must be reported to the IRB Office immediately.
4. **Amendments:** Changes to the protocol must be requested by submitting an Amendment to the IRB Office for review. The Amendment must be approved by the IRB before being implemented.
5. **Informed Consent:** Information must be presented to enable persons to voluntarily decide whether or not to participate in the research project.

This electronic document provides notification of the review results by the Institutional Review Board.

TEXAS A&M UNIVERSITY
DIVISION OF RESEARCH AND GRADUATE STUDIES - OFFICE OF RESEARCH COMPLIANCE

1186 TAMU
College Station, TX 77843-1186
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FAX 979.862.3176
http://researchcompliance.tamu.edu

Institutional Biosafety Committee | Institutional Animal Care and Use Committee | Institutional Review Board

DATE: 18-Apr-2008

MEMORANDUM

TO: GOODSON, PATRICIA

FROM: Office of Research Compliance
Institutional Review Board

SUBJECT: Amendment

Protocol Number:	2006-0366
Title:	Perception of Genetic Risk in Decision-Making (PGRID) by College Students
Review Category:	Expedited
Approval Period:	18-Apr-2008 **To** 17-Jul-2008

Approval determination was based on the following Code of Federal Regulations:

45 CFR 46.110(b)(2) - Minor changes in previously approved research during the period of (one year or less) for which approval is authorized.

Provisions: Minor edits to survey instrument

This research project has been approved for one (1) year. As principal investigator, you assume the following responsibilities

1. **Continuing Review:** The protocol must be renewed each year in order to continue with the research project. A Continuing Review along with required documents must be submitted 30 days before the end of the approval period. Failure to do so may result in processing delays and/or non-renewal.
2. **Completion Report:** Upon completion of the research project (including data analysis and final written papers), a Completion Report must be submitted to the IRB Office.
3. **Adverse Events:** Adverse events must be reported to the IRB Office immediately.
4. **Amendments:** Changes to the protocol must be requested by submitting an Amendment to the IRB Office for review. The Amendment must be approved by the IRB before being implemented.
5. **Informed Consent:** Information must be presented to enable persons to voluntarily decide whether or not to participate in the research project.

This electronic document provides notification of the review results by the Institutional Review Board.

This is great. You may conduct your research here at UH now. Please let me know if there are any problems.

Debbie Comeaux, CIP
Research Compliance Specialist
(713) 743-9215
dcomeaux@uh.edu

-----Original Message-----
From: Heather Honore [mailto:hhhonore@hlkn.tamu.edu]
Sent: Sunday, August 13, 2006 2:30 PM
To: Comeaux, Debra L
Subject: RE: Honore Request for New Protocol

Ms. Comeaux:

Thank you very much for responding to my e-mail so quickly. I have attached a revised copy of the flyer to this e-mail. Please let me know if you need any additional information and I will send it ASAP.

Thanks again,
Heather

Heather H. Honore, MSW
Doctoral Student in Health Education
Graduate Research Assistant
Texas A&M University
Department of Health & Kinesiology
Mail Stop 4243
College Station, TX 77843-4243
hhhonore@hlkn.tamu.edu

~~"My weapons are peaceful, for only by peace can peace be attained."~~

Paul Robeson

Everything looks fine and you can continue your study here at UH. Please let me know if you have any questions or if anything changes in your study.

Debbie Comeaux, CIP
Research Compliance Specialist
(713) 743-9215
dcomeaux@uh.edu
-

----Original Message-----
From: Heather Honore [mailto:hhhonore@hlkn.tamu.edu]
Sent: Wednesday, October 25, 2006 3:57 PM
To: dcomeaux@uh.edu
Subject: Honore Request for Protocol Revision

Ms. Comeaux:

I am writing to you in order to request a revision to my UH IRB protocol. The study consent form and flyer have been revised to reflect the addition of one general admission movie ticket as potential compensation for participating in the PGRID study. I am attaching copies
of the revised consent form, flyer, and TAMU revision approval letter for the UH IRB records. Thank you in advance for your assistance in this
matter.

Regards,
Heather

Heather H. Honore, MSW
Doctoral Student in Health Education
Graduate Research Assistant
Texas A&M University
Department of Health & Kinesiology
Mail Stop 4243
College Station, TX 77843-4243
hhhonore@hlkn.tamu.edu

~~"My weapons are peaceful, for only by peace can peace be attained."~~

Paul Robeson

From: Heather Honore
Sent: Thu 8/10/2006 1:06 PM
To: dcomeaux@uh.edu
Subject: Honore Request for New Protocol

Ms. Comeaux:

My name is Heather Honore and I am currently a doctoral student at Texas A&M University (TAMU). I am writing to you in order to initiate a new IRB protocol at the University of Houston. My study titled, "Perception of Genetic Risk in Decision-making (PGRID) by College Students" recently underwent an expedited review by the TAMU IRB, and was deemed a minimal risk study (PI: Patricia Goodson, PhD and Co-PI: Heather H. Honore). As per our previous telephone conversation, I am sending the following summary of the study's objective, recruitment and sampling procedures, as well as any anticipated risks and benefits to participants in lieu of completing a formal IRB application.

The PGRID study intends to answer the question "how does perception of genetic risk influence sexual and reproductive decision-making by college students, including mate selection?" PGRID is a qualitative study using in-person interviews and focus groups conducted with convenience samples of Texas A&M University and University of Houston students. Students who meet inclusion criteria (i.e., 18 years of age or older, and currently enrolled at the University of Texas at San Antonio) and who are selected to participate will be contacted by study personnel to explain the study procedures and obtain consent. The study will involve a maximum of 10 in-person interviews and 50 focus group participants at UH.

Recruitment will consist of flyers, advertisement with academic departments and student organizations; and personal contact with course instructors and classes. Participants will respond to qualitative, open-ended questions on genetic health-related knowledge, skills, attitudes, and behaviors. Their responses to qualitative questions will be transcribed from audiotapes, coded and analyzed for statistical relevance, themes and content. Demographic data will be used for aggregate data reporting. Results of this qualitative study may generate additional research questions or studies to be submitted for future IRB approval.

There are minimal risks to participating in this study. Such minimal

risks might include loss of confidentiality and feelings of discomfort or strong emotions generated by discussion of family history of genetic traits during interviews and focus groups. To minimize these risks, all participants will receive code numbers on study documents rather than be identified by name or other personal identification information. For example, transcripts of focus group questions will contain code numbers, not names. Signed consent forms and other study materials will be kept in a locked filing cabinet in the PI's office. In addition, the PI and Co-PI have undergone CITI and/or NIH training in ethics and methods of maintaining confidentiality. (Electronic copies of certificates may be furnished upon request.)

There are no benefits for participating in this study. A potential benefit for some participants might be increased awareness of their own family history of genetic traits (i.e. special characteristics, "gifts," and diseases). All participants will receive in-kind tokens such as t-shirts, books, or food.

I hope that this explanation provides you with enough information to award approval for the study to be performed at UH. If you have any remaining questions, please feel free to contact me via e-mail (hhhonore@hlkn.tamu.edu <mailto:hhhonore@hlkn.tamu.edu>) or telephone (979-450-5364). I am also attaching copies of the TAMU IRB application and approval letter, consent form, study advertisement, and list of qualitative questions for in-person interviews and focus groups for your records.

Best regards,

Heather

UH-GCSW Class of 2005

UTSA The University of Texas at San Antonio
Office of Research Integrity and Compliance

FWA# 00003861

September 25, 2007

Patricia Goodson, Ph.D.
Heather H. Honore
Texas A&M University
Department of Health and Kinesiology
MS 4243
College Station, TX 77843-4243

NOTICE OF REAPPROVAL

Dear Dr. Goodson and Ms. Honore:

Re: IRB # 06-325
Title: "Perception of Genetic Risk in Decision-making (PGRID) by College Students"
Site: UTSA

In accordance with Federal regulations for continuing review, the above referenced protocol was reviewed on September 25, 2007, by Expedited Review on behalf of the Institutional Review Board and was reapproved under the following Expedited Categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)

The study is open to enrollment and data are being analyzed.

It was determined that the research continues to pose minimal risk to the participating subjects, and that continuing review will occur annually. The consent form has been stamped with the new approval period. This action will be conveyed to the Institutional Review Board at its next convened meeting.

RESPONSIBILITIES OF PRINCIPAL INVESTIGATOR FOR ONGOING PROTOCOLS:

1. Conduct the study only according to the protocol approved by the IRB; promptly report any protocol, policy, or regulatory deviations or violations to the IRB;

UTSA The University of Texas at San Antonio
Office of Research Integrity and Compliance

FWA #00003861

Date: April 18, 2008

To: Patricia Goodson, Ph.D.
Heather H. Honore
Texas A&M University
Department of Health & Kinesiology

From: Judith W. Grant, Ph.D., CIP
Director, Institutional Review Board

Judith W. Grant, Ph.D., CIP

Subject: IRB #06-325
Title: "Perception of Genetic Risk in Decision-making (PGRID) by College Students"
Site(s): UTSA

Requests:	Action:
☐ **Revised Consent Form(s)**	☒ **Approve**
☒ **Protocol Modification/Addendum**	☐ **Clarification required**
☐ **Change in Title**	☐ **Disapprove**
☐ **Addition/Deletion of Investigator**	
☐ **Spanish Translation of Consent Form(s)**	
☐ **Conditions Met**	
☐ **Ads/Flyers/Recruitment Material**	
☐ **Other:**	

Comments: Approval was given on April 18, 2008,, to your amendment request. The modifications include:

1) Finalized Survey.
2) PGRID Screen Out Page, Thank You Page, and Voluntary Form regarding drawing entry.

VITA

Name: Heather Helaine Honoré

Address: Dept. of Health and Kinesiology
c/o Dr. Patricia Goodson
Texas A&M University
College Station, TX 77843-4243

Email Address: heather.honore@yahoo.com

Education:

B.S., Biology (Scientific Inquiry concentration), The Louisiana Scholars' College at Northwestern State University of Louisiana, 1997

M.S.W., Social Work (Mental Health concentration), University of Houston, 2005

Ph.D., Health Education, Texas A&M University, 2008

Professional Experience:

Consultant, Texas Department of State Health Services, Women, Infants, and Children (WIC) Program Grant, Institute for Obesity Research & Program Evaluation, Texas A&M University, 2007-2008

Graduate Teaching Assistant, Department of Health & Kinesiology, Texas A&M University, 2007-2008

Graduate Research Assistant, Department of Health & Kinesiology, Texas A&M University, 2005-2008

Research Assistant (Program Evaluator/Data Analyst), Datatude, Incorporated, 2004-present

Research Assistant (Clinical Research Coordinator), University of Texas Medical Branch, 2002-2003

Associate in Research (Research Technician/Laboratory Manager), Duke University Medical Center, 2000-2001